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Including: Social Work, Humanitary Health Intervention, Nursing, Missionary Work

# CLINICAL SOCIAL WORK AND HEALTH INTERVENTION

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## *Bridges between Social Work and Chronic Health Care*

### Original Articles

- ✓ BUILDING BRIDGES BETWEEN SOCIAL WORK AND PRENATAL PSYCHOLOGY
- ✓ IN MEMORIAM PROF. MUDR. PHDR. PETER G. FEDOR-FREYBERGH, DRSC., DR.H.C.
  - ✓ PSYCHOSOCIAL IMPACT OF COVID-19 ON ELDERLY/SENIOR POPULATION
- ✓ QUALITY OF LIFE AND PROFESSIONAL ACTIVITY OF WORKING-AGE PATIENTS AFTER STROKE
- ✓ COMPARATIVE STUDY OF THE PERCEPTION OF THE ROLE OF A SOCIAL WORKER IN HOSPITALS IN THE CZECH REPUBLIC AND SLOVAKIA DURING THE COVID-19 PANDEMIC
- ✓ A STUDY ON SELECTED ASPECTS OF THE QUALITY OF LIFE OF PEOPLE IN REMISSION AFTER CANCER TREATMENT WITH THE USE OF THE INDIVIDUAL IN-DEPTH INTERVIEW TECHNIQUE
  - ✓ SOCIO-PSYCHOLOGICAL IMPACTS OF TERMINAL ILLNESS ON PATIENTS AND THEIR SPOUSAL RELATIONSHIP
- ✓ THE WELL-BEING OF CHILDREN AND YOUNG PEOPLE: THE CONTEXT OF SOCIAL SERVICES FROM THE PERSPECTIVE OF THE CAPABILITY APPROACH
  - ✓ CLINICAL, DEMOGRAPHIC AND PSYCHOLOGICAL PREDICTORS OF QUALITY OF LIFE IN PATIENTS WITH OSTEOARTHRITIS
- ✓ BARRIERS IN EDUCATION OF CHILDREN FROM SOCIALLY DISADVANTAGED ENVIRONMENT
  - ✓ MIGRATION AS PURSUIT OF THE SOCIAL DETERMINANTS OF HEALTH
- ✓ PSYCHOSOCIAL ASPECTS AND QUALITY OF LIFE IN CANCER PATIENTS UNDERGOING SURGERY
  - ✓ TEACHING LEARNING METHODOLOGY IN TIMES OF COVID-19 PANDEMIC: A CASE STUDY
  - ✓ IMPORTANCE OF MIDWIFERY CARE IN THE PREVENTION OF POSTPARTUM DEPRESSION

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## Editorial

# Building Bridges Between Social Work and Prenatal Psychology

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## In Memoriam Prof. MUDr. PhD. Peter G. Fedor-Freybergh, DrSc., Dr.h.c.

This issue of *Clinical Social Work and Health Intervention* is dedicated to deceased co-founder of our Journal and President of the *International Society of Prenatal and Perinatal Psychology and Medicine*, Director of the First Department of Perinatal Psychology and Medicine, Honorary Doctor and holder of Honorary Degrees and Medals of multiple Universities in Poland, Czechoslovakia, Italy, Malaysia, etc, Doctor of Medicine and Psychology and Editor in chief of four Medical Journals: *Acta Neurosa Superioris Rediviva*, *Neuroendocrinology Letters*, *Clinical Social Work and Health Intervention* and *Int. Journal of Prenatal and Perinatal Psychology and Medicine* (1-4). Together with his spouse Lili Maas, ArtD., who added to the exact science, arts and her heart and love, all of those Journals were not only reading of naked facts and theories, or science but both were teaching us to accept psychology, social work and medicine as art culture and love, what is more than science and knowledge, more than facts. (From the letter of St. Paul and two letters of St. Peter, New Testament)

Among his students and Fellows, Professors and Associate Professors, two were Ministers of Health in the EU and outside of EU. They are not only his successors but real constructors of bridges between medicine, psychology, social work, theology and arts.

In an era of health threats and social disasters, psychological deprivation and absence of solidarity, he came with his spirit at the right time, and he stays with his spirit still, and long, long into the future.

Therefore, we do not wish only „*requiem aeternam dona tibi Domine Petrus et lux perpetua luceat tibi*“, („Lord, grant you Peter eternal rest and may perpetual light shine on you“) but also Peter, please stay with us with your Mystery and Art and Love Forever! We love you but we also need you and remember your message „*Turris fortis mihi Deus*“ („God is my strong tower“).

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3. Clinical social work and health Intervention Vol. 12.2021.4
4. Int. Journal of Prenatal & Perinatal Psychology & Medicine Vol. 35.2021

# Psychosocial Impact of COVID-19 on Elderly/Senior Population

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## Abstract:

Senior population is one of major social work and healthcare issues in highly developed countries. The aim of this study was assessing the late psychosocial consequences in seniors in

Vienna and Bratislava after the first and second waves of the COVID-19 pandemics.

The results suggest that elderly patients in contrast to children and adolescents suffer significantly more late psychosocial consequences after having coronavirus acute or chronic disease.

This paper is dedicated to Prof. Dr.h.c mult Peter G. Fedor Freyberg, ScD.

## Introduction

The combination of homelessness senior age/elderly with multiple comorbidities together with seasonal epidemic diseases such as influenza, COVID 19 etc. is a triple deadly synergy.(1-2) Elderly people who live alone or are homeless have poor nutritional and social status (1-12); access to preventive or therapeutic medications and vaccines for prevention; therapy not only against SARS and influenza but also for other comorbidities such as chronic obstructive PD, hypertension. Another population at risk are small children and pregnant women among migrants (3-12). After being ill on COVID or other epidemic viral disease, post-COVID syndrome with psychosocial consequences frequently appear. The aim of this research is to assess if homeless seniors have more frequently psychosocial consequences than younger or middle-aged homeless population.

## Methods

In an open label comparative multi-centric prospective study performed in Košice and Bratislava, two cities connected by train and bus service in 2 hour intervals, we analyzed psychosocial consequences on 102 social work clients in 2 shelters or mobile intervention teams. (Oasis vs. Jarna & Mea Culpa). A questionnaire in brief but guided dialogue plus Q&A setting were used. 34 were seniors (age 63 and more) and 67 middle age or younger adults (29 to 62 years). Inclusion criterium was homelessness in the history at least for 3 months in last 2 years (incl). Inclusion criterium was a verbal history or undergoing COVID-19 in 2000/21 season (until June 30, 2021 from Apr 1, 2020).

## Results and discussion

Psychosocial consequences such as: poor nutritional status; depression; fatigue disability for seasonal work; loss of appetite; weakness were compared. Depression, fatigue and weakness - were more significantly ( $P < 0.01$  and  $0.001$ ) present in elderly versus non-elderly group.

Surprisingly, ability of seasonal work was not different among both groups, probably due to the low proportion of homeless individuals in the study, willing to accept seasonal work (13).

Access to medications both for COVID and non-COVID medicines (14-16) was low but non-significant among both groups. Another unexpected finding was willingness to receive vaccine both for influenza and COVID was high in both groups in contrast to previous study in children (17-19). The explanation of this phenomenon may result from similar findings from COVID studies in elderly patients and in migrants and homeless (19-24) where those groups accept vaccines more openly in contrast to primary healthy, younger and socially secure population (1-29).

## Conclusion

In conclusion, the results were stimulating in terms of willingness to accept vaccination both for COVID or pandemic influenza, due to the poor social status and threat for vulnerable groups, with no difference between seniors and non-senior adults.

Late consequences, such as depression fatigue of weakness were significantly more observed among seniors, other possible consequences of past coronavirus infection such as poor nutritional status after infection or ability/willingness

to work were similarly frequently represented in both groups.

Those findings can be used for the work of interventional social workers or vaccination/testing teams in pending homeless especially in elderly age, to easier combat the third pandemics wave and mitigate the upcoming seasonal influenza season.

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# Quality of Life and Professional Activity of Working-Age Patients after Stroke

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## Abstract:

**Background & objectives:** Stroke is one of the most common and severe diseases in terms of the economic burden on society. The aim of this study was to assess the quality of life of people after stroke in the context of professional activity, considering the time since stroke.

**Material & methods:** To assess the quality of life, a shortened Polish version of the World Health Organization Quality of Life Questionnaire (WHOQOL-Bref) was used. The study was

conducted on a group of 279 people with the first stroke diagnosed.

**Results:** The statistically significant relationship was observed, considering the period after stroke in groups: 6-12 months; 13 months-2 years; 2-5 years from the onset of stroke. The correlation between professional activity of people after stroke and their quality of life was statistically significant in: the somatic sphere; the social sphere; the environmental sphere.

**Conclusions:** Undertaking professional activity by people who had a stroke significantly affected the self-assessment of their quality of life and satisfaction with the quality of health, regardless of the period since the onset of the stroke.

## Introduction

It is estimated that until 2030 the number of deaths around the world caused by stroke might be as many as 7.68 mln people and it will be one of more serious medical problems. Regardless of geographical location, stroke is a major cause of permanent disability among adult people often disqualifying them from professional life.

In Poland 1/3 of people who survived stroke die within a year from the moment first symptoms appear. Another 1/3 of people suffer from considerable functional deficits. It mainly shows as hemiparesis, aphasia, dysfunction of higher nervous activity. Those people require permanent care of other people. In the other group of sick people functional impairment is not as serious and they are partially able to exist on their own. This high death-rate in Poland is affected by co-existent diseases, especially cardiovascular diseases (high blood pressure, heart diseases) as well as lung diseases (1). Stroke is one of the most common and most serious diseases considering economic burden of society (2). Oftentimes, it results in people losing their jobs and lower standard of life. Data regarding people returning to work after a stroke differ from 1% to 91% depending on a country according to Hartke & Trierweiler and from 19% to 73% according to Treger *et al.* (3, 4). Frequency of stroke is connected to age, more and more often it happens to people in working age. Returning to professional life after a stroke depends on many factors, including: the kind of stroke; neurological deficits; the kind of work that a person did before the stroke (2). Cerebrovascular accident causes permanent neurological damage, which very often makes it impossible for people who suffered from it to come back to the professional life they had beforehand.

Cardiovascular accident causes permanent neurological damage, which makes it impossible for many people to come back to professional life (5). No chance for professional comeback after sick leave caused by stroke involves negative consequences for the sick person – lower quality of life (2). In medical science, there is a definition accepted by WHO which defines the quality of life as: perception of one's social status within such aspects as culture, hierarchy of values, relations to one's objectives, desires, interests, norms designated by environmental conditions (6). The cognitive goal of this paper is analyzing the correlation between the quality of life of people in working age after stroke and professional activity (working – not working) depending on the time that has passed since the stroke: 1<sup>st</sup> group 6–12 months; 2<sup>nd</sup> group 13–24 months; 3<sup>rd</sup> group 2–5 years since the stroke. At the same time, a connection was searched for: the connection between the quality of life and the time that passed since the stroke.

## Material and Methods

Presented research is only a part of realizing the project of analyzing the quality of life of people of working age after a stroke. The research was done by means of a diagnostic survey. To measure the quality of life a questionnaire with standardized scale by WHOQOL-Bref was used. It was validated to Polish conditions by L. Wołowicka & K. Jaracz. This questionnaire enables evaluation of the correlation between psychophysical factors such as family relations or professional activity of both a healthy person and a person afflicted with different diseases (7). The questionnaire contains 26 closed questions scored 1–5 points and makes it possible to get

a profile of life quality in four fields: motor; psychological; social; environmental. The scoring of the fields is positive – the more points the better the quality of life. Initial results were transformed to the scale 0-100 (8).

The obtained results were documented by means of a specially prepared Microsoft Excel program. Statistical evaluation was carried out by means of STATISTICA program. Correlations between the scales were searched for by means of specifying Pearson's rank order coefficients.  $P < 0.05$  test probability was accepted as crucial.

The analysis concerned randomly chosen people of working age. The following criteria for choice were taken: age 25-59 for women; 25-64 for men; first stroke diagnosed and defined according to WHO criteria; time after the stroke – at least 6 months, but no longer than 5 years; patient's consent to be examined. People who did not meet the criteria were excluded from the examination. 279 persons were examined – all with recognized first stroke. 243 persons suffered from ischemic stroke; 36 persons from hemorrhagic stroke. Those people were treated in 3 Rehabilitation Departments in the south of Poland. Rehabilitation treatment was directed at the aftermath of stroke. People who were examined were divided into 2 groups – 1st group patients who returned to work after the stroke; 2nd group patients who continued to take social benefits and did not come back to professional life. Next, the examined group was divided into 3 subgroups. The time after the stroke was taken into account. The 1<sup>st</sup> subgroup were patients 6–12 months after the stroke (103 persons); 2<sup>nd</sup> subgroup patients 13 months–2 years after the stroke (60 persons); 3<sup>rd</sup> patients 2 years–5 years after the stroke (116 persons). The choice of periods of time was influenced also by basic rehabilitation stages: early hospitalization; functional rehabilitation (up to 12–24 months); time of functional adaptation (up to 5 years) (9). Also, world clinometric recommendations in the field of quality of life and the influence of disease on it were taken into account. They recommend the time for its evaluation after the condition of the patient is stabilized (e.g. after 3, 6, 12 months) because earlier results may not be reliable (6, 10).

The percentage of people who resumed work after stroke was 17.56% (49 persons). Before stroke more than half of the examined people

(55.10%) used to do white-collar jobs, whereas 20.41% of examined people used to do blue-collar jobs. The average time from the stroke until the examination was  $27 \pm 19.63$  months, in the group of people working  $28.02 \pm 19.42$  months; in the group of people not working  $26.02 \pm 19.69$  months. Average age in the examined group was  $54.5 \pm 7.52$ ; in the group of not working people  $57.17 \pm 6.76$ . The age difference between working and not working people was 5.2 years. In the group of working people, the majority completed secondary education, however in the group of not working people – vocational education. Obtained information shows that the majority of examined people suffered from ischemic stroke (243 persons); hemorrhagic stroke (36 persons); right-sided paresis was diagnosed among 50.18% (140 persons); left-sided among 49.82% (139 persons). In the group of working people after stroke left-sided paresis dominated (61.22%), however, in the group of not working people right-sided paresis dominated 52.61%. The majority of the people examined (47.67%) stated that they were in a poor economic situation. The people who resumed professional work after stroke (38.78%) stated that their economic situation was good; 52.1% of not working people declared their economic situation as bad. The majority of examined people (58.78%) were married; the rest - 20.79% - are widowers or widows; 13.26% are single (Table 1).

## Results

Statistically significant correlation between professional activity and self-evaluation of life quality was observed. It depended on the time that passed from the stroke with the exception of people 13–24 months from falling sick. Detailed analysis of the research results by means of WHOQOL-Bref questionnaire showed positive statistically significant correlation with the level of significance  $p = 0.001$  in a group of patients: 6-12 and 25-60 months since the stroke between professional activity and their satisfaction from the quality of life. The obtained result confirms that resuming professional activity is very important for people after stroke because it generates higher appreciation of their life quality in relation to not working people. The result showed the level of appreciation of life quality regarding their professional life in juxtaposition with self-

**Table 1** Sociodemographic parameters of the examined patients (n=279) after stroke in working age.

Variables	Category of answer	Professional activity					
		Working		Not working		Total	
		n	%	n	%	n	%
Gender	Woman	31	63.27	100	43.48	131	46.95
	Man	18	36.73	130	56.52	148	53.05
Age	Mobile	9	18.37	14	6.09	23	8.24
	Not mobile	40	81.63	216	93.91	256	91.76
Marital status	Not married	7	14.29	30	13.04	37	13.26
	Married	31	63.27	133	57.83	164	58.78
	Divorced	6	12.24	14	6.09	20	7.17
	Widower	5	10.20	53	23.04	58	20.79
Education	Primary	4	8.16	41	17.83	45	16.13
	Vocational	14	28.57	94	40.87	108	38.71
	Secondary	17	34.69	66	28.70	83	29.75
	University	14	28.57	29	12.61	43	15.41
Paresis side	Right sided	19	38.78	121	52.61	140	50.18
	Left sided	30	61.22	109	47.39	139	49.82
Economic situation	Bad	13	26.53	120	52.17	133	47.67
	Average	17	34.69	74	32.17	91	32.62
	Good	19	38.78	36	15.65	55	19.71
Professional status before stroke	White collar worker	27	55.10	52	22.61	79	28.32
	Blue collar worker	10	20.41	83	36.09	93	33.33
	Farmer	8	16.33	26	11.30	34	12.19
	Other	4	8.16	69	30.00	73	31.74

assessment of health. The quality of life was higher than satisfaction from health. The results were shown in Table 2.

The analysis of obtained results by means of t-student's test and Pearson's correlation coefficient shows statistically significant correlation between professional work and assessment of satisfaction from one's health in groups of patients no longer than two years since stroke. However, regarding the group longer than 2 years since the stroke such correlation was not seen. Professional activity correlated positively with assessment of satisfaction from health in groups no longer than 2 years from the stroke until the time of examination. The level of correlation significance between variables was  $p=0.000$  in the group 6-12 months and  $p=0.039$  in the group 13-24 months since the stroke. The obtained result

suggests that professional activity generates higher self-assessment of one's health, but only in cases no longer than 2 years from the stroke (Table 2).

Analysis of examination result obtained by means of t-Student's test and Spearman's correlation coefficient showed statistically significant correlations between professional activity and quality of life in the somatic sphere in the mentioned time periods to the advantage of working people. The juxtaposition of the correlation between professional activity and quality of life in the somatic sphere in each of the analyzed time periods shows the existence of positive and statistically significant correlations between all the assessed variables. Those results suggest that professional activity generates a higher quality of life in somatic sphere. The level of correlation

**Table 2** Correlation between professional activity and assessment of the quality of life and health.

	Time from the stroke	Professional work		T-student's test	r-Pearson's correlation coefficient
		yes	no		
Life quality assessment (Bref1)	6-12 months	3.75	2.95	t=-3.446 p=0.001	r=0.324 p=0.001
	13-24 months	3.44	3.16	t=-0.803 p=0.425	r=0.105 p=0.425
	25-60 months	3.79	3.11	<b>t=-3.859</b> <b>p=0.000</b>	<b>r=0.295</b> <b>p=0.001</b>
Health assessment (Bref2)	6-12 months	3.50	2.60	<b>t=-3.661</b> <b>p=0.000</b>	<b>r=0.342</b> <b>p=0.000</b>
	13-24 months	3.44	2.69	<b>t=-2.112</b> <b>p=0.039</b>	<b>r=0.267</b> <b>p=0.039</b>
	25-60 months	3.13	2.78	t=-1.547 p=0.125	r=0.143 p=0.125

between variables in all time periods was  $p=0.000$  (Table 3).

Examining the influence of professional activity on the psychological sphere in each time period it was observed that there were statistically significant correlations in groups of patients 6-12 and 25-60 months after the stroke. The analysis of the correlation between professional activity and psychological sphere in the two above mentioned time periods showed statistically significant positive correlations between variables. The level of correlation significance between variables was  $p=0.000$  in the group 6-12;  $p=0.009$  in the group 25-60 months after the stroke. The results show that professional activity affects the level of life quality in the psychological sphere (Table 3).

Analyzing the obtained results the examination of professional activity and the social sphere significant differences were seen as well as correlations between variables in all 3 analyzed time periods since the stroke. The level of correlation significance between variables was respectively:  $p=0.002$  in the group of sick people 6-12 months from the stroke;  $p=0.018$  – in the group 13-24;  $p=0.047$  – in the group 25-60 months from the stroke. Among working people quality of life in social sphere is higher than in the group of people who do not work (Table 3).

The obtained results of Pearson's t-Student's test and Pearson's correlation coefficient show numerous statistically significant differences in different time periods between professional activity and the environmental sphere. The analysis of correlation between variables shows that there are positive and statistically significant correlations in all the examined areas. The level of statistical significance of the correlation between variables was  $p=0.000$  in the group of sick people 6-12 months;  $p=0.037$  in the group of sick people 13-24 months and  $p=0.003$  in the group 25-60 months after the stroke. The results prove that working people have a higher quality of life in the environmental sphere than people who do not work (Table 3).

Another area of research was checking to what degree the time that passed since the stroke affects the quality of life of people of working age after stroke among working and not working people. Analyses were done with the use of ANOVA tests - *Analysis of Variance* and Spearman's correlation coefficients were used. No correlation between the time which passed since the stroke and the feeling of satisfaction from the quality of life and satisfaction from one's health was found. The time which passed since the stroke does not affect the quality of life in the spheres examined by means of WHOQOL-Bref.

**Table 3** Correlation between professional activity and quality of life spheres in the group of examined patients

Quality of life spheres	Time since the stroke	Professional work		t-Student's test	r-Pearson'e correlation coefficient
		yes	no		
Somatic sphere	6-12 months	62.56	40.61	<b>t=-5.717</b> <b>p=0.000</b>	<b>r=0.494</b> <b>p=0.000</b>
	13-24 months	64.11	41.25	<b>t=-4.095</b> <b>p=0.000</b>	<b>r=0.474</b> <b>p=0.000</b>
	25-60 months	59.92	44.43	<b>t=-4.763</b> <b>p=0.000</b>	<b>r=0.407</b> <b>p=0.000</b>
Psychological sphere	6-12 months	67.19	40.70	<b>t=-4.790</b> <b>p=0.000</b>	<b>r=0.430</b> <b>p=0.000</b>
	13-24 months	58.33	44.96	t=-1.755 p=0.085	r=0.225 p=0.085
	25-60 months	57.00	45.52	<b>t=-2.665</b> <b>p=0.009</b>	<b>r=0.242</b> <b>p=0.009</b>
Social sphere	6-12 months	69.87	52.66	<b>t=-3.216</b> <b>p=0.002</b>	<b>r=0.305</b> <b>p=0.002</b>
	13-24 months	70.11	52.57	<b>t=-2.443</b> <b>p=0.018</b>	<b>r=0.305</b> <b>p=0.018</b>
	25-60 months	64.33	55.12	<b>t=-2.008</b> <b>p=0.047</b>	<b>r=0.185</b> <b>p=0.047</b>
Environmental sphere	6-12 months	68.13	50.23	<b>t=-4.402</b> <b>p=0.000</b>	<b>r=0.401</b> <b>p=0.000</b>
	13-24 months	66.78	52.96	<b>t=-1.132</b> <b>p=0.037</b>	<b>r=0.270</b> <b>p=0.037</b>
	25-60 months	63.71	53.29	<b>t=-3.035</b> <b>p=0.003</b>	<b>r=0.273</b> <b>p=0.003</b>

The quality of life of working people after stroke does not differ significantly from people who do not work (Table 4).

## Discussion

Assessing the quality of life of the people after stroke is not easy because it concerns many spheres of people's lives in a subjective way. Analyzing the quality of life one should take into account not only physical and psychological as-

pects but also social and environmental relations (11). Weber-Rajek *et al.* state that questions about psychological potential of somatic life became important when civilization diseases appeared. Such diseases are defined by psychosocial factors and stroke is one of them (12). The results of this analysis show that professional activity heavily affects quality of life. The somatic sphere was one of the spheres most affected because it makes it possible for more efficient people to start work.

**Table 4** Correlation between the time since the stroke and life involving professional activity considering examined patients' professional activity

Quality of life	Professional work	Time since the stroke			Total	ANOVA(F)	Spearman's correlation coefficient
		6-12 months	13-24 months	25-60 months			
Assessment of life quality	No	2.95	3.16	3.11	2.95	F (2.227)=0.982 p=0.376	Rsp=0.067 p=0.312
	Yes	3.75	3.44	3.79	3.75	F (2.460)=0.646 p=0.529	Rsp=0.062 p=0.671
Assessment of health	No	2.60	2.69	2.78	2.69	F (2.227)=0.853 p=0.427	Rsp=0.084 p=0.206
	Yes	3.50	3.44	3.13	3.31	F (2.460)=0.838 p=0.439	Rsp=-0.188 p=0.197
Somatic sphere	No	40.61	41.25	44.43	42.28	F (2.227)=1.693 p=0.186	Rsp=0.123 p=0.063
	Yes	62.56	64.11	59.92	61.55	F (2.460)=0.384 p=0.683	Rsp=-0.054 p=0.711
Psychological sphere	No	40.70	44.96	45.52	43.57	F (2.227)=1.438 p=0.240	Rsp=0.109 p=0.098
	Yes	67.19	58.33	57.00	60.57	F (2.460)=1.530 p=0.227	Rsp=-0.213 p=0.141
Social sphere	No	52.66	52.57	55.12	53.62	F (2.227)=0.436 p=0.647	Rsp=0.052 p=0.429
	Yes	69.87	70.11	64.33	67.20	F (2.46)=0.491 p=0.615	Rsp=-0.084 p=0.566
Environmental sphere	No	50.23	52.96	53.29	52.06	F (2.227)=0.964 p=0.383	Rsp=0.061 p=0.356
	Yes	68.13	66.78	63.71	65.71	F (2.46)=0.414 p=0.663	Rsp=-0.113 p=0.441

People like that have a higher quality of life right from the start. It was proved by the research done by Zawadzka *et al.* (11). Professional work affects the quality of life (11). The possibility of earning money is a strong motivational factor to come back to work for people after stroke, however, the importance of making money becomes smaller in comparison with other psychological benefits. It is emphasized by Cholewa *et al.* or Hartke & Trierweiler (13, 14). Taking into consideration the professional activity of people after stroke in the presented material, Zawadzka's *et al.*'s opinions about the lower quality of life

among not working people is confirmed (11). According to Kowalczyk *et al.* (15) not doing any professional work largely negatively affects the quality of life. In examination done by Tasiemski *et al.* was proved that possibility of starting a job after stroke is one of the most important factors affecting the quality of life (16).

Results of numerous foreign research investigations show that possibility of starting a job is one of the most important factors affecting quality of life after stroke (17, 18, 19). Research done by Muli *et al.* (20) show higher quality of life of working people than people who do not work.

Research done by Muss *et al.* in a group of 105 patients in Denmark with the use of the SSQoL-DK scale shows a better quality of life of working people than people who do not work (21). Westerlind *et al.* showed that people who resumed professional work after stroke had a higher quality of life than people who did not (2). Koch *et al.*, Medin *et al.* noticed that resuming work may have a positive effect on good mental mood of people after stroke and satisfy many psychosocial needs (22, 23). Maruthappu *et al.* came to think that unemployment is a potential risk factor of death in the case of cerebrovascular diseases (24). In research done by Vestling *et al.*, 41% resumed work, although changes of employers, working hours, and duties appeared. People who resumed work reported a much higher level of subjective good mood and satisfaction from work (17).

Research done by Tasiemski *et al.* shows that there were 24% of working people after stroke, however the whole group of examined people included only 25 persons (16). Examination done in a group of 279 people showed that there was 17.56% of people who resumed work after stroke. It is important to emphasize that if people who do blue-collar jobs do not get fully operational before stroke they are forced to make a living from a social benefit that they receive, which in turn results in their lower economic status and lower quality of life. Resuming work after stroke among people of working age should be a priority target of holistic rehabilitation because it provides the feeling of social identity and is connected to improving one's self-esteem and satisfaction from life. When resuming work one must think about existing barriers hindering employment of people after stroke. It may be physical barriers, cognitive barriers, and also psychosocial and environmental factors, which is shown by Wang *et al.* (25). Time which passed since stroke is a frequent factor of including in the examination. In self-examination, the analysis of patients referred to 6 months to 5 years with the following division: 6-12, 13-24 and 25-60 months since the first stroke with the aim of assessing future treatment results and their effect on the quality of life (26). The connection between time since stroke and quality of life of professionally active and not active people after stroke. Obtained results allow a conclusion that time that passed since

stroke is not statistically important in assessing quality of life of examined people. Assessment of the level of the quality of life done by Kowalczyk *et al.* showed that there is need for multi-directional research with the aim of improving level of life quality in all its spheres, in the case of people after stroke considering their life situation, functional status and the sick person's expectations (7). This research is part of realizing the strategy and health policy of the country included in The National Health Program (2016-2020) whose aim is "prolonging life in health; improving health and the quality of life of people as well as reducing social health inequalities".

## Conclusions

1. Starting professional work by people after stroke considerably affected higher self-esteem; quality of life; satisfaction from health independent of the time since stroke. It emphasizes the role of professional activity as a factor in improving the quality of life.
2. The people after stroke who start professional work value quality of life much higher than people who do not work. Quality of life in social and environmental aspects was valued highest. Favorable effect of professional activity on somatic and psychological aspects of life of working people in comparison to people who do not work.
3. As a result of life being considerably longer, the aim of health and social policy should be improving quality of life for people after stroke of working age by means of improving chances of resuming work after stroke. Changing profession will help to do that. Likewise, the need for an holistic approach in the rehabilitation of people after stroke is on the rise.

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# Comparative Study of the Perception of the Role of a Social Worker in Hospitals in the Czech Republic and Slovakia during the COVID-19 Pandemic

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Original Article

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## Abstract:

This research study is focused on the perception of the role of a social worker by hospital nurses in the Czech and Slovak Republic during the COVID-19 pandemic.

**Aim of the study:** The main aim of the research study was to find the opinions of nurses from the Czech and Slovak Republic on a social worker who works in a hospital during a coronavirus - COVID-19 pandemic and then compare their opinions in helping patients

**Research sample and setting:** The research sample of the study consisted of 75 nurses with higher professional education (Czech Republic), university education of the first and second degree (Czech Republic, Slovak Republic), who were together with social workers in the front line in hospitals at the time of

the coronavirus pandemic COVID-19. All participating respondents were informed about the purpose of the research study and the completion of the online questionnaire.

**Statistical analysis:** The mathematical-statistical method chi-square test of the independence of the criteria of individual research hypotheses was used to compare the interviewed respondents in the Czech Republic and Slovakia.

**Results of the study:** Medical staff at the time of the COVID-19 pandemic was satisfied with the social worker, as evidenced by the research study and their answers in the questionnaire survey. It is clear from the results of the research survey that the participants perceived the social worker positively during the COVID-19 pandemic.

## Introduction

The pandemic of the SARS-CoV-2 virus, simply referred to as Covid-19, complicated the lives of perhaps every social group of various professions, including social workers and medical staff in hospitals in every country, with no exception of the Czech and Slovak Republic.

The role of every healthcare facility in the Czech or Slovak Republic, especially hospitals, is to provide healthcare, and during a pandemic, it is acute healthcare. Each pandemic will reflect the readiness and cooperation of the individual components - within the staff who work in the hospital. If the hospital does not have enough medical staff, especially during the Covid-19 pandemic, covid patients and healthcare professionals are assisted by people from related professions, e.g. from the Department of Social Work, specifically social workers in healthcare.

Social Work in healthcare is a specialized activity in the field of Social Work. It can be perceived as a professional provision of social services focused primarily on helping clients, their families and the community in which clients are located. Further, it improves or maintains proper functioning in relation to their own health (Hrozenská, Drzsíková, 2016), which can be seen in the practical activities of the Covid-19 pandemic. According to Kuzníková (2011, p. 18), the role of social work in healthcare is "using the influence of the psychosocial sphere on the disease to adapt better, to overcome difficulties, to motivate for treatment and cooperation, and finally to improve the quality of life." Therefore, it is necessary to use complex care for the client, i.e. the patient.

The Covid-19 pandemic culminated in the Czech Republic around 12 April 2020, when a total of 4,800 people with Covid-19 were registered, of which 436 were hospitalized, including hundreds of patients who were in serious condition. The number of infected and sick began to increase again during the summer of 2020, a significant outbreak of the disease (per capita) was the capital city of Prague in large numbers visited by foreign tourists. In the following months, the incidence of the disease spread to almost the entire republic. However, in contrast to the spring culmination, there was no similar increase in hospitalizations; the spread of the disease among the younger population in the Czech Republic contributed to this. The culmination of the whole situation was in September 2020, when the Czech Republic ranked among the most affected countries in Europe in terms of the number of newly infected per million inhabitants (Central, 2020). Individual data of the Czech Republic within September 2020 were unfavorable, the number of newly detected cases exceeded 1,000 persons for the first time and the daily increase was greater than 2,000 persons. The whole situation eased in the summer months. At the beginning of 2021, however, the Covid-19 pandemic returned in the form of a second wave.

According to the Ministry of Health of the Czech Republic, there are officially 30,363 deaths (victims) in Covid-19 in the Czech Republic in July 2021.

As part of the culmination of the Covid-19 coronavirus pandemic, not only the number of hospitalized patients in the Czech Republic grew in the Czech Republic, but also the number of people in severe condition requiring intensive

care grew. The Ministry of Health of the Czech Republic gradually published new data, from which it was possible to read the current numbers of hospitalized, bed capacity, available hospital staff and support staff, including many social workers.

The development of the Covid-19 pandemic in Slovakia was initially milder than in comparison with the Czech Republic, as evidenced by individual statistics and measures adopted by the Slovak government. The first case was confirmed in Slovakia in March 2020, on the basis of which measures were taken by the Ministry of Health and the Central Crisis Staff against the epidemic, an emergency situation was declared, schools were closed, and an emergency situation began to apply. Since March 2020, the number of people positive for Covid-19 has grown by dozens of people in each self-governing region. On 15 March, the Government of the Slovak Republic declared a state of emergency for state hospitals in Slovakia, which was extended to other medical facilities and social service homes. In April, the number of infected and the number of victims rose. At the end of May, Slovakia had 1,522 cases and 28 victims, another victim was added only after two months on 30 July, and 2,292 cases had already been infected.

In connection with the arrival of the second wave of the pandemic on 1 October, a state of emergency came into force in Slovakia again. At the turn of October and November, area testing took place over three weekends. For the first time on 24 and 25 October in Orava and in the Bardejov district, nationwide testing took place in the whole territory of Slovakia on 31 October and 1 November. Slovakia began to tighten anti-pandemic measures, between 21 October and 13 November the daily increase in new cases exceeded 2,000. There were not enough beds in the hospitals for patients with COVID-19, the medical staff was exhausted and there was a shortage. Students of medical and health faculties, social workers and volunteers helped.

After a slight improvement in the second half of November, daily case increases began to increase again in December. Between December 18 and January 9, they attacked the 4,000 mark; on the last day of the year there were 6,315 new cases. From December 28, deaths began to exceed 100 per day. The highest number of 204 vic-

tims occurred on January 4. In February 2021, Slovakia became the worst in the world in the number of deaths and hospitalized cases per capita. According to the Ministry of Health of the Slovak Republic, there are officially 12,541 deaths (victims) in Covid-19 in Slovakia as of July 2021.

## **Methodology – Research design**

The issue of social and healthcare is very closely connected (Kuzniková, 2011, p. 19), as evidenced by the practice within individual health and health and social facilities, where social work in healthcare plays a role. According to Kovalčíková (In Mojtoová, 2008, p. 18), the goal of social work in healthcare is to provide the necessary support; support; accompaniment; assistance to a client who is in some way disadvantaged due to his health condition.

The research is devoted to the perception of the role of a social worker by nurses in hospitals in the Czech and Slovak Republics during the COVID-19 pandemic. The sample of our comparative study to determine the goal consisted of deliberately selected participants, i.e. nurses who worked with a social worker in the COVID-19 pandemic in the hospital. We deliberately selected this research sample so that we could compare participants by territory, namely the Czech Republic and Slovakia. The author Miovský (2006, p. 135) describes “as a deliberate (sometimes also purposeful) selection of a research sample such a procedure when we purposefully search for participants according to their certain properties. The selection criteria is the currently selected (determined) property (or the manifestation of this property) or the state of belonging to a certain social or other group. This means that, based on a set criteria, we purposefully search for only those individuals who meet this criterion, and at the same time are willing to participate in the research.” For the research survey, we chose an online questionnaire research method, which kept the anonymity of our participants. We chose quantitative research because it is designed for humanities research and is suitable for a wide selection of participants.

The aim of the research was to find whether nurses perceive the social worker during the COVID-19 epidemic in hospitals as a benefit, and whether they are satisfied with the coopera-

tion with the social worker during the provision of assistance to patients during the COVID-19 pandemic in the hospital.

In the analysis and interpretation of the collected data, we first used the mathematical classification of the first degree, then we statistically verified the research hypotheses. Pearson's chi-square test was used to confirm or refute the hypotheses. The chi-square test is one of the statistical methods that allows you to verify that a random variable has certain predetermined probability distributions. This test is the basic and most widely used contingency table independence test, as reported in the study. "The research is based on the idea of comparing the observed frequency and the expected abundance. The contingency table is used in statistics to illustrate and clearly show the relationship between two characters" (Ferjenčík 2000, p. 237). The observed frequencies represent data obtained from participants, the expected frequency is obtained by calculating the following formula:

$$G = \sum_{i=1}^r \sum_{j=1}^s \frac{(n_{ij} - n'_{ij})^2}{n'_{ij}}$$

The chi-square test of good agreement is based on the assessment of the difference between the actual (observed) frequencies of occurrence of the values in the sample and the expected frequencies, corresponding to the respective assumed probability distribution. When calculating the  $\chi^2$  test of good agreement, we assume that the null hypothesis holds, and if the calculated value of  $\chi^2$  is less than 0.05, then we reject the null hypothesis because the difference between the observed and expected frequencies was a random factor, Hendl (2004, p. 56).

A questionnaire survey was conducted with nurses in the Czech Republic (Prague) and Slovakia (Košice). A total of 75 people participated in completing the questionnaire. More than 150 respondents were contacted, other respondents rejected us and did not want to participate in research due to workload. The observed characteristics of the respondents were gender and territory, ie the states of the Czech Republic and the Slovak Republic.

From Table 1 it is clear that we divided the participants into two categories, according to the territory (state) and gender to which the research questionnaire was personally given for comple-

**Table 1** Number of participants

Parti- cants	Czech Republic		Slovak Republic	
	Male	Female	Male	Female
Count	9	36	3	27
Overall	45		30	
	75			

tion. Out of the total number of 75 participants (nurses) in the hospital, 36 are women and 9 men from the Czech Republic, and from the Slovak Republic there are 27 women and 3 men.

## Results

### Hypothesis 1

**H01** Nurses from the Czech and Slovak Republic perceive the work of a social worker in a hospital during the COVID-19 epidemic as beneficial.

**HA1** Nurses from the Czech and Slovak Republics do not perceive the work of a social worker in a hospital during the COVID-19 epidemic as unfavorable.

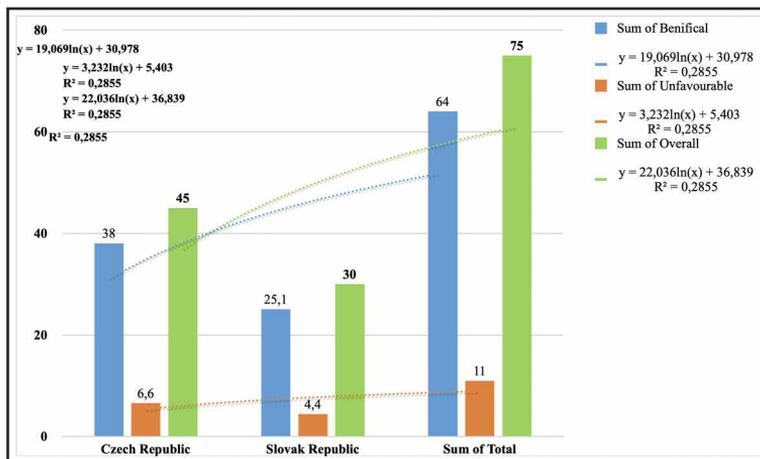
The result of the research survey shows that out of 75 addressed participants (nurses) from hospitals in the Czech and Slovak Republics, up to 64 consider and perceive a social worker as a benefit in hospitals within the COVID-19 epidemic. In the research, we also encountered the opposite view, where 11 nurses do not perceive a social worker as a benefit in the hospital during the COVID-19 pandemic. These individual responses were subsequently verified by the Chi-square test, which was 0.071. Based on this result, the alternative hypothesis H1 was rejected and the null hypothesis H0 was accepted - Nurses from the Czech and Slovak Republic perceive the work of a social worker in a hospital during the COVID-19 epidemic as beneficial.

Based on the calculation of the significance of the Chi-square test, we came to the following conclusions which we present in the previous contingency table and Graph 1. It can be stated that the observed frequency showed that out of the total number of 75 participants, 64 perceive the presence of a social worker at hospitals at the time of the COVID-19 epidemic as a benefit. The opposite opinion had 11 nurses who do not perceive the social worker as a benefit in the hospital at the time of COVID-19. In the subsequent cal-

Contingency Table 1 of the Chi-square test calculation

Expected frequency		Beneficial	Unfavourable	Overall	
Nurses	Czech Republic	38,04	6,6	n. <sub>j</sub> 45	
	Slovak Republic	25,06	4,4	n. <sub>j</sub> 30	
Total sum		n <sub>1</sub> 64	n <sub>2</sub> 11	n. <sub>j</sub> 75	
		Significance level	α 5 %	Chi-square test indication	G 0,071
After substituting into the formula, the test criterion is based: G 0,071				Evaluation:	
Critical value: $\chi_{(1-\alpha)}$ ; df 3,841				$\chi_{(1-\alpha)}$ ; df 3,841 > 0,071	
At the level of significance of 5%, the null hypothesis H01 of nurses from the Czech and Slovak Republics perceive the work of a social worker in a hospital during the COVID-19 epidemic as beneficial, about the independence of individual features, because the value of the tested criterion is less than the critical value.					

Contingency Graph 1 of the calculation of the significance of the Chi-square test for hypothesis 1



ulation of the chi - square, its result was set at 0.071. The significance value of 0.071 is less than the critical 3.841. The graph also showed the logarithmic sum and the logarithmic curve - based on a five-step calculation - of the total sum of the participants' responses, in our case the nurses who worked with a social worker during the COVID-19 epidemic in the hospital.

**Hypothesis 2**

**H02** Nurses from the Czech and Slovak Republic are satisfied with the cooperation of a so-

cial worker in a hospital during the COVID-19 epidemic.

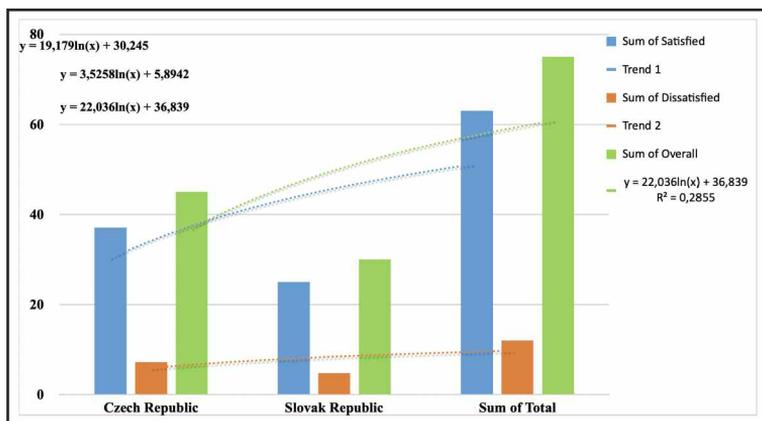
**HA2** Nurses from the Czech and Slovak Republics are not satisfied with the cooperation of a social worker in a hospital during the COVID-19 epidemic.

The result of the research investigation shows that out of 75 addressed participants (nurses) from hospitals in the Czech and Slovak Republics, up to 63 are satisfied with the cooperation of a social worker during the COVID-19 epidemic. 12 participants were of the opposite opin-

Contingency Table 2 of the Chi-square test calculation

Expected frequency		Satisfied	Dissatisfied	Overall	
Nurses	Czech Republic	37,8	7,2	n. <sub>j</sub> 45	
	Slovak Republic	25,2	4,8	n. <sub>j</sub> 30	
Total sum		n <sub>1</sub> 63	n <sub>2</sub> 12	n. <sub>j</sub> 75	
		Significance level	α 5 %	Chi-square test indication	G 0,017
After substituting into the formula, the test criterion is based: G 0,017				Evaluation:	
Critical value: $\chi_{(1-\alpha); df} 3,841$				$\chi_{(1-\alpha); df} 3,841 > 0,017$	
At the significance level of 5% null hypothesis H02 Nurses from the Czech and Slovak Republic are satisfied with the cooperation of a social worker during the COVID-19 epidemic in the hospital, about the independence of individual features, because the value of the tested criterion is less than the critical value.					

Contingency Graph 2 of the calculation of the significance of the Chi-square test for Hypothesis 2



ion, i.e. they were not satisfied with the cooperation during the COVID-19 pandemic. Subsequently, we verified the individual answers with a Chi-square test, which turned out to be 0.017. Based on this result, the alternative hypothesis H2 was rejected and the null hypothesis H02 was accepted - Nurses from the Czech and Slovak Republics are satisfied with the cooperation of a social worker in a hospital during the COVID-19 epidemic.

Based on the calculation of the significance of the Chi-square test, we came to the following conclusions, which we present in the previous

contingency table and graph 2. It can be stated that the observed frequency showed that a total of 75 participants were 63 nurses satisfied in the COVID-19 epidemic. 12 sisters were of the opposite opinion, i.e. not satisfied. In the subsequent calculation of the chi - square, its result was set at 0.017. The significance value of 0.017 is less than the critical value of 3.841. The graph also showed the logarithmic sum and the logarithmic curve - based on the calculation of five degrees - from the total sum of the answers of the participants, in our case the nurses.

## Conclusions of Research Results

The aim of this research study was to find the opinions of nurses from the Czech and Slovak Republics on a social worker presence and then compare their opinions in helping patients in the hospital during the corona of the COVID-19 viral pandemic. To fulfill this aim, we set two secondary research aims and defined two hypotheses, the null and the alternative hypothesis. Within the methodology of the selected quantitative research survey, a research sample of nurses was presented, namely a total of 75 patients, the questionnaire method of data collection and statistical evaluation of these collected data was verified by a good agreement test, chi-square test, where we could rule out one of the hypotheses. and thus confirm the second hypothesis.

The first side research aim was to determine whether there is a significant difference between nurses in the Czech and Slovak Republics in the area of perception of the contribution of a social worker in a hospital during the COVID-19 epidemic. Based on the answers of the participants verified by the chi-square test, the null hypothesis was accepted - H01 Nurses from the Czech and Slovak Republics perceive the work of a social worker in a hospital as beneficial during the COVID-19 epidemic.

The result therefore shows that nurses in the Czech and Slovak Republics perceive the work of a social worker in a hospital during the COVID-19 epidemic as beneficial. The results of the survey are relevant because a small sample of only 75 participants from two hospitals was found, in Prague and Košice. It would be necessary to compare these data in all hospitals in the Czech Republic and Slovakia, where social workers work. Social workers in healthcare have: complex professional and professional (theoretical-practical) knowledge; participation in satisfying not only the social needs of the client; the ability of independent highly professional work as stated by the author Laca (2016). Professors of social work Mačkinová and Kopinec (2019) point to the general competencies of social work in healthcare as a “functional manifestation of good management and recognition of the professional role of a social worker which includes expertise and ability to reflect adequate context and sensitively apply professional values.”

The second aim was to find, in case of satis-

faction or dissatisfaction, cooperation of a social worker with nurses in hospitals. Based on the answers of the participants verified by the chi-square test, the null hypothesis H20 was accepted. Nurses from the Czech and Slovak Republic are satisfied with the cooperation of a social worker in the hospital during the COVID-19 epidemic.

The results show that out of 75 participants, 63 were satisfied in cooperation with a social worker. Even in this case, we consider the result to be relevant, because it also confirms the result of the survey where individual participants (nurses) from the Czech and Slovak Republics expressed disagreement, but the verification of individual data showed us the confirmation of the null hypothesis.

As we can see from this research study, the role of a social worker in the hospital is well perceived in both countries, in the Czech and in Slovakia Republics. A health and social worker is basically a social worker working in a healthcare facility who knows both social and health issues. This combination of knowledge is essential for social work in health care facilities. To set up good patient care, the healthcare professional needs to understand the patient's illness. The link between health and social care is constantly evolving, and as we can see is particularly needed in the current COVID-19 pandemic.

## Conclusion

When a new coronavirus pandemic spread during 2020, various measures began to be taken in all countries to mitigate its spread and consequences. One of these measures was the restriction of outings and social contacts, which most significantly affected working and especially school life, as school teaching in the school year 2020/2021 was interrupted in the Czech Republic and Slovakia and was not resumed by the end of the calendar year 2020. It was renewed only for kindergartens, the first stage of primary schools and the last years of secondary schools, which could return to schools on the basis of the COVID vending machine.

The presented research study deals with the perception of a social worker by nurses in hospitals in the Czech and Slovakia Republics during the COVID-19 pandemic. The entire issue of the corona wave of the COVID-19 viral epidemic

has affected the whole of human society in every area. Society's response to the pandemic has resulted in health, social and economic disruption. This has led to: the postponement or cancellation of several cultural, social and sporting events; a widespread shortage of supplies of medical supplies; exacerbated panic fears in society.

The above results show that the participants (nurses) in hospitals at the time of the corona wave COVID-19 were satisfied with the social worker. We can say that the Covid-19 pandemic has so far affected the functioning of various professions, not excluding social work and social workers around the world. The pandemic we have been facing for the last year is increasingly uniting our society not only professionally but also humanly. It is therefore necessary for people to be aware of the meritorious and professional work that a multidisciplinary team will do and it is not only in hospitals. However, we must not forget the friendly gestures, understanding and mutual help that is needed to overcome COVID-19 in our society.

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# A Study on Selected Aspects of the Quality of Life of People in Remission after Cancer Treatment with the use of the Individual in-depth Interview Technique

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Original Article

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## Abstract:

**Background:** A characteristic feature of cancer is, among other things, that even after successful oncological treatment, the patient cannot close this chapter of life and the experience of being a cancer patient. In oncology there is no unambiguous definition of a patient as a healthy person.

**Methods:** The study covered a group of 20 people. In the conducted tests the diagnostic survey method was introduced. The technique of individual in-depth interviews was used. The respondent could fully express his or her own feelings, emotions, thoughts and experiences.

**Results.** The respondents stated that positive emotions appeared with the completion of treatment, but indicated that the feelings were not related to the sense of healing but only to the completion of tiring therapeutic procedures. Some respondents complained about the feeling of chronic fatigue. Fatigue was not only related to the physical sphere, although everyone confirmed that the side effects of the therapy persisted for some time. The respondents paid more attention to mental fatigue, which had various forms, e.g.: anxiety about possible relapse; functional losses; feeling of loss caused by radical treatment. Out of 20 respondents, 4 persons indicated a loss of health, especially the sense of joy and happiness, self-esteem, self-confidence, social contacts, family and time.

**Conclusions:** The research group consisted of 20 respondents, which limits the possibility of formulating generalized conclusions, but indicates various directions of possible improvement and, most importantly, shows how the thinking about cancer can be changed.

## Background

A characteristic feature of cancer is, among other things, that even after successful oncological treatment, the patient cannot close this chapter of life and the experience of being a cancer patient. In oncology there is no unambiguous definition of a patient as a healthy person. The definition of a patient cured from a cancer completely, if they feel healthy for five years after the treatment, is no longer in use. Studies indicate that relapse of the disease may occur even after many years of treatment.

A person in remission faces a big dilemma. On the one hand, joy should prevail, but on the other hand, there is the awareness of the presence of cancer, that will stay for a very long time. This raises a question of how to help the patient to live a happy life despite experiencing the disease [1]. Life after the end of cancer therapy changes because it reevaluates the perception of all aspects of bio-psycho-specialist functioning. A person can continue to have health problems related both to the treatment and the location of the cancer. In particular, health will require care, including regular check-ups, usually accompanied by stress and a sense of fear of a possible relapse [2].

**The aim of the present study** was to learn about the selected factors determining the quality of life of people after the completed anticancer treatment in the period of remission and to try to

specify the guidelines for further care of patients and their families and/or significant persons.

## Methods

In the conducted tests the diagnostic survey method was introduced. The technique of individual in-depth interviews was used. There were individual conversations between the respondent and the investigator, without the presence of third parties, in an atmosphere of confidentiality and understanding. The respondent could fully express his or her own feelings, emotions, thoughts and experiences.

An interview scenario, developed on the basis of standardized research tools for assessing the quality of life of people with diagnosed cancer, was applied as a tool. It had an established scheme, but sometimes for the sake of full clarity, auxiliary questions were introduced. **The first part** of the questionnaire concentrates on socio-demographic issues: age; education; occupation; family situation; information about the respondent's disease unit; type of treatment applied. **The second part** concerned psychosocial problems, feelings and emotions of the respondent at different stages of the disease starting from the moment of diagnosis, through the period of treatment to the present day. **The third part** focused on the physical and intellectual spheres.

The study was carried out after receiving

**Table 1** Clinical characteristics of the study group

P1	F	34	Breast cancer	Surgery Chemotherapy
P2	F	31	Bone-based carcinoma	Surgery Chemotherapy
P3	F	38	Spinal cord lining	Surgery Radiotherapy
P4	F	30	Ovarian cancer	Surgery Chemotherapy
P5	F	42	Cervical Cancer	Surgery Radiochemical Therapy
P6	F	43	Breast cancer	Surgery Chemotherapy
P7	F	26	Hodgkin's lymphoma	Chemotherapy Radiotherapy
P8	F	35	Breast cancer	Surgery Chemotherapy Radiotherapy
P9	F	22	Hodgkin's lymphoma	Chemotherapy
P10	F	25	Ewig's sarcoma	Chemotherapy Radiotherapy
P11	F	23	Hodgkin's lymphoma	Chemotherapy Radiotherapy
P12	F	39	Ovarian cancer	Surgery Chemotherapy
P13	F	37	Breast cancer	Surgery Chemotherapy Radiotherapy Hormonotherapy
P14	F	43	Breast cancer	Surgery Radiotherapy Chemotherapy
P15	M	34	Fibre star	Surgery Radiotherapy (Gamma Knife)
P16	M	41	Thyroid cancer	Surgery Radiodem treatment
P17	M	36	Testicular cancer (Semen)	Surgery Radiotherapy
P18	M	28	Nucleus cancer (Nematode)	Surgery Chemotherapy
P19	M	48	Scuttlefish	Surgery Chemotherapy
P20	M	29	Brain lining	Surgery Radiotherapy

a positive opinion from the Bioethics Committee (No. KBKA/28/O/2015, on 14.05.2015). Respondents came from the vicinity of Krakow in Poland; participation in the study was voluntary; the principle of confidentiality was maintained. The meetings lasted more than 2.5 hours, but some of the respondents were met twice because of too much mental strain caused by one, long meeting or because they chose so.

The study covered a group of 20 people, 14 women and 6 men, reporting to the Primary Care Clinic. The criteria for inclusion in the study are as follows: patients with past cancer; patients who completed cancer treatment in the remission phase of the disease; patients who have undergone cancer treatment in the last 5 years and are currently in the remission phase.

The characteristics of the examined group of patients as follows: the respondents were 22 to 48 years old; 6 of the examined women were married, 2 in separation. The remaining 8 respondents were unmarried, of which 5 had never been

married and 3 women divorced during the illness. In the group of the examined men, 5 were married, 1 was a widower. 12 respondents had offspring. As for the education in the group: there were 9 people with higher education; 6 with secondary education; 5 with vocational education. At the time of the research: 4 were studying in different schools (3 of them working at the same time); 11 people were working professionally; 6 people were not working (including 1 student); 3 people lived on a pension. Clinical characteristics of the respondents are presented in Table 1.

## Results

The respondents stated that positive emotions appeared with the completion of treatment, but indicated that the feelings were not related to the sense of healing but only to the completion of tiring therapeutic procedures. They were not happy about „winning the battle for life“. During the interviews, the questions were asked: „How do you see yourself nowadays? Do you think of yourself

as a fully healthy person?“ Only two men felt this way while the others talked about the current stage - the remission of the disease – and did not see it as the end of therapy or a complete cure of the cancer. Moreover, the emotions connected with the end of the therapy were described as a feeling of some kind of loss of security, care and even a loss of life role they had already got used to.

Some respondents complained about the feeling of chronic fatigue. Fatigue was not only related to the physical sphere, although everyone confirmed that the side effects of the therapy persisted for some time. Respondents paid more attention to mental fatigue which had various forms, e.g.: anxiety about possible relapse; functional losses; feeling of loss caused by radical treatment. Respondents also described their outbursts of irritation, anger and frustration. Most of the respondents spoke about the intensification of negative emotions just after finishing the treatment. Some considered this time to be more burdensome than even the time when they were undergoing treatment.

*„Of course, at first I was happy to start living a normal life. But what does „normal“ mean? The effects of the treatment were lasting for a long time. I was depressed, I had trouble concentrating and remembering, which again frustrated me, so I burst into anger and fury. I wasn't fit for work, because I was feeling tired all the time. Okay, the cancer is gone but I still feel like a wreck sometimes, and it's been already 2 years“. P15*

Negative feelings did not appear immediately after the therapy. It was difficult for patients to understand these emotions: 7 benefited from help of a psychologist; 3 were treated by a psychiatrist due to anxiety disorders and depression. Our own research shows that mental and emotional disorders intensified within about a half to one year after end of treatment. Most of respondents stated that the feeling of being in the doldrums occurred at the time when the positive emotions connected with the end of the treatment were fading away. The period immediately after the end of the therapy was usually described positively, as patients felt joy, relief and sometimes euphoria. However, when asked about the reason for these feelings, only two people replied that they were happy because they were already healthy. The others felt

relieved and happy about the end of the tiring treatment. Research has shown that the most intense mental problems were described by people whose treatment was long lasting, preceded by a crippling operation. Those people did not receive or rarely received psychological or psychiatric assistance.

The study showed that 5 of the 6 men and 5 of the women surveyed said they were enjoying life and no longer thinking about the disease. The women felt supported by relatives and friends. Many of the people surveyed did not have full families, or their marriages broke up during the time of illness.

Below, there are excerpts from conversations with 3 patients: 2 treated by a psychiatrist; 1 in care of a psychologist.

*„The end of treatment was a moment of joy for me. I was bursting with energy and I was glad I wouldn't have to be bothered anymore. Although the effects of the treatment were slowly subsiding, the disease took away something more important than 2 years of my life, loss of hair, nails, breast or teeth. It took away my joy of life. I started to notice it when the euphoria I felt when the doctor said the illness was over. My family can't understand it: 'You are healthy - why are you not happy?' Many people probably think the same way: We should jump with joy, enjoy the smallest things and the sky should be more blue for us. Meanwhile, I've been treating my depression for several months. My husband, who used to be the funniest guy in the world for me, can't make me laugh anymore. And as I used to live from chemo to chemo, I live from check-up to check-up now. And the sky is the same as it was. The miraculous redefinition of life did not occur to me“. P1*

*„Everyone thought, and so did I, that when the treatment was over, life would be like it was before. Despite the fact that my family and friends quickly forgot about my illness and everything came back to normal for them, unfortunately for me it did not. I am no longer the same person, I can't be happy and I can rarely laugh happily. I used to be a cheerful girl, I was all over the place. Unfortunately, when you leave the hospital, you are happy that it is over, that you can come back to life shyly, in small steps. And then comes the time of check-ups and everything is there again; memories come back; you want to*

vomit when you enter the parking lot. A thousand thoughts per minute. And that is the end of my joy. How am I supposed to feel healthy if I can't forget my condition? It's impossible to forget that there is a hidden cancer inside you and if just one cell „goes crazy“ - as my doctor said... I can't stop thinking about it.“ P9

„A few months after the treatment, something happened to me. I was looking for symptoms of the disease all the time and with every smallest change I went to the doctor. At my clinic they think I'm crazy. But when the treatment was over, I felt like someone threw me out of my home. During that year of treatment I attached myself to the hospital, I became a part of it. I received care and support there, sometimes it was better and sometimes worse, but the most important was that my cancer was monitored and dealt with there. And suddenly, what? The end? The worst thing is that the cancer hasn't disappeared completely, although all the time I believed that when treatment ends, you are healthy. But the doctor put me right, even though I would rather not hear that. He said that there were residual lesions which we would have to watch at check-ups, but there would be no more treatment possible. I thought I would be fine after all this year of treatment. When it became clear it didn't work that way, I went crazy. Even at the beginning, when I was diagnosed for the first time, it wasn't as bad as when I realized that I could go through it again. I was slowly falling into... I don't really know into what... I went to a psychologist who sent me to a psychiatrist and he said I had an anxiety disorder. It's better now, but it was really bad. I practically didn't sleep and I kept thinking about a relapse all the time. My heart was throbbing and I was constantly thinking about dying, not only my own Heath but also my loved ones. I sensed danger from all directions.“ P7

### **Sense of loss due to the occurrence of disease.**

Out of 20 respondents, 4 persons indicated a loss of health, especially the sense of joy and happiness, self-esteem, self-confidence, social contacts, family and time.

„Before my illness, I was a completely different person; I was a party boy; it was difficult for me to sit still. The illness made me a bore. Now, after work, I prefer to stay in my room and read a book or watch something. I shut myself away.

I don't have the energy to attend parties, which obviously makes my wife happy. I don't know why it is like that, but a lot of things I used to be happy about, stopped interesting me now. I used to like being the center of attention, I had a lot of friends, now I don't even want to talk to them“ P20

„I've become so gloomy and withdrawn. I used to laugh a lot, now it's really hard to make me laugh. Besides, when I was sick, I didn't feel like seeing anyone or going out, so... when my therapy was over, no one gave me a ring, my phone was silent, and remains silent.. Now, the thought of contacting anybody after such a long time is really embarrassing for me“. P8

„Sometimes I think I won't be alive for long since I've been through this treatment. I know what may happen after this kind of therapy. My aunt was also sick when she was young, she died of a heart attack at 55. I know I have a genetic predisposition. I already have heart problems. I feel sorry for myself and I am overwhelmed with bitterness that I had to get sick. I feel worse than any other people of my age“ P9

„The illness took away my health, but also the time when I could have had fun instead of getting sick. I think that what I feel most sorry for are the wasted 2 years of my life.“ P11

In addition to the losses associated with the disease and oncological treatment, the subjects indicated positive aspects of the illness. Most often they were related to the changes of their lifestyles, focusing on their own dreams; tightening and strengthening family ties; etc.

„I didn't take care of myself before. Because of my illness: I gave up smoking; I took up exercising; I started to sleep normally; I finally live like a human being. I gave up extra work and spend more time with my family.“ P15

„I've always had a 1,000 ideas and plans, but I never realized them. When I pulled myself together after the treatment, I decided that it was time for changes; life is short and there may be no time at all. Before, I did not like to spend money on holidays, not now. I go to a Dance school' I jumped with a parachute; I plan to do all the things I've always wanted to do. When I got sick, I received a signal that I can't just stand still and live life half-heartedly. I take more care of myself than before, and I noticed that my husband takes more care of me than before. I also

try to help women who go through the same experiences as me. At least this is the best I can do". P5

### **The sense of loss related to the course of oncological treatment.**

Symptoms occurring during the course of anticancer treatment, sometimes despite their remission, in some people still cause great trauma. This may contribute to mental disorders.

„When my colleague came out of the bathroom and I saw what remind of her hair, I was speechless; her hair came off her head in the shower! We were treated for the same problem; we had the same chemotherapy; only she had already been halfway through her therapy. Then I realized I was going to look like her. And in a month I looked the same. I didn't want to see myself in the mirror, I was disgusting. I could not get over the loss of hair and it was the most awful experience for me. I hardly ever left home then though before, when I still had my hair. Even chemotherapy didn't stop me from going out to a pub with my friends.“ P9

„I was most concerned about my appearance. I felt ugly, fat, just disgusting. I was jealous of my friends when they came to visit me, I was angry that I looked like this. I swelled up on steroids. My toenails and hair fell off. The hair was the worst. It was thinning out, it was just everywhere, on cushions, on the floor, on clothes, I even had it on my plate when I ate. My hair was like leaves falling down from the tree in autumn and every time it reminded me of my illness. Eventually, there was just a few ridiculous hairs left so my Mom took a razor and shaved them off. We were both howling doing it.“ P11

The feeling of loss related to chemotherapy and radiotherapy was about hair loss, nails, skin elasticity, vitality. Usually, emotions accompanying these losses are sadness and depression, regret, anger, frustration, jealousy, shame. Men did not pay much attention to appearance.

Surgical treatment can be associated with mutilation, is irreversible and has a huge psychological impact, which was confirmed by respondents. The interviews were difficult, bringing tears and bitterness in many cases, but there were also those who even made jokes about the loss suffered. Men undergoing an orchidectomy did not consider it as a loss that would cause the in-

tensification of negative emotions, but rather did not pay attention to it.

„(...) I was thinking about losing my breast: What I'm going to look like? What is my husband going to say when he sees me after the surgery? In fact, I haven't come to terms with the fact that I don't have my breast because whenever I see these disgusting scars and when I sometimes touch this place, I cry straight away. I know I had to do it, but it's hard to accept it. I've been through hair loss, too, but it's grown back now, But my breast hasn't. The Amazons encouraged me to do the reconstruction, but I don't want another surgery, I prefer not to touch this place at all.“ P13

„Losing your breasts is like losing being a woman. You know, I would have let the doctors cut them both off because I wanted to live but they have always been the symbol of my femininity for my husband. He said at the beginning that the surgery would not change anything. When I was sick I lived with an illness, but after the treatment you come back home, where your husband wants to hug you and suddenly you realize that you don't have breasts; you won't be able to undress because you are ashamed. I have felt like that for a very long time; you can say that we are separated by my disease(...). I go to a psychologist, but I don't think I can ever accept it for the rest of my life. The worst thing is that it still reminds me of the sickness“ P8

„Before the surgery, I was still hoping, praying that they wouldn't remove everything from me. But it didn't work; prayers didn't work; I became a 30 year-old woman with menopause; without the possibility of giving birth to a child; a defective one, I'm not fit for anything. I was a strong believer, now I don't believe in anything, I even sang in a Schola. But when God decided that I don't deserve to be a mother, I don't believe in him either (...) I was busy with my career, studies, work... I didn't think of children, after all, I could give birth to them later, I thought I had time, and here there was no time. I recently met a cleric from the Schola. He was very comforting, I mean, he wanted to, but it didn't do any good. When he said that faith works wonders, it made me furious. No faith can make my uterus grow back. The cancer took literally everything from me.“ P4

„I had broken bones and had to have my leg

amputated. When I was lying on the operating table, I thought I didn't want to wake up at all, that I didn't want to live without my leg. I really didn't want to live then. For 6 months after the surgery I had phantom pains, I wanted to kill myself. I suffered from depression and I was being treated for it for some time. I didn't want to talk to anyone, not even to my child. And then it started, rehabilitation and a long way to where I am now. I can walk, my whole family and friends are collecting money for my new super-leg. I've learned to live with it, but sometimes I have days when everything annoys and upsets me. Sometimes, I take it out on my family. Even recently I had a situation when I woke up and saw my little son playing with my prosthesis. I got mad and started screaming „Give me that leg back!“ When I realized what I was saying, I cried out of laughter. Cancer may have taken my leg but it didn't take away my sense of humor...“ P2

### **Family support, intimate relationships. Relationships in marriages and families are presented below.**

„You know what it's like when a guy is sick - it is just unbearable. I feel sorry for my wife for these few months. But I love her even more. If it wasn't for her, I don't know how I would have handled it. She is my private angel. I guess the kids could feel something was wrong, too, because when they saw my head bandaged, I guess I never got so many kisses from my daughter. She was very worried about me. After the surgery and the irradiation I had memory problems for some time, I couldn't recover, the whole family was helping me in this, we all became very close because of my illness“ P15

„Before that, we lived just ordinary, everyday life with my wife. When I got sick, I appreciated having her. I'm very grateful for everything. Only because of her I could feel good. I know how deeply she was affected by my illness. The baby / she is on maternity leave / and me - in hospital. But I believe that because of this little toddler everything went so fast, I didn't think about the disease, I just had to get back to life as soon as possible“ P18

„(...) I have the greatest family in the world, even though my son sometimes plays with my prosthesis or tells his friends that his mother is a robot. These moments of horror that we all ex-

perienced together; this pain and suffering that my family shared with me, all these moments brought us together so strongly. I have the most wonderful husband under the sun. If it wasn't for him, I don't know how it would have ended. Throughout the whole time of rehabilitation he cheered me up, motivated and encouraged me. If it wasn't for him, I wouldn't be able to walk so beautifully now. I don't know if I would manage to pull myself together at all. Recently, we have danced for the first time since then. Family is the most important aspect of all this. It must be terrible not to have support from the family.“ P2

Among the spouses, the men were more often talking about hiding their bad moods or ailments because they did not want to show their wives their weaknesses. On the other hand, the female patients usually hid their emotions and problems from their children, for the sake of their well-being. Some women have received and continue receiving support from their spouses, but other problems have arisen that make the spouses move away from each other.

As the results of the research presented earlier show, many patients experience psychological problems like anxiety disorders and depression after oncological treatment. Some of them benefit from psychological support, but the majority of the respondents do not want to get help despite their poor psychological condition in the belief that this must be the case that it is a normal phenomenon. A few people also pointed out that they might consider getting psychological support, but they are afraid of being labelled crazy. In Poland, the use of psychological and psychiatric support is still stigmatized. The women surveyed who experience such emotions, are not able to build proper family relations. They often mention conflicts escalating due to their partners' misunderstanding of their deeds, as they change during the treatment and after the therapy. These, in turn, cause increasing tension and often lead one of the parties to step back, to separate or even divorce.

In conversations with women about the problems of family functioning, they admit that they do not cope with emotions even though they know about them. The most frequently mentioned here were: outbursts of anger and irritation; oversensitivity; unjustified claims; rejection of closeness of the partner. The respondents often

said that these situations were caused by the lack of understanding on the part of the partner.

An important aspect of everyday life is the sexual sphere, especially for the women who underwent mutilating treatments. Some of them are able to cope with this situation others tend to avoid any physical nearness. Their partners cannot understand it, feeling rejected and unfulfilled, which can result in outbursts of anger and resentment towards the women. Respondents often mentioned that their spouses blame them for their rejection or lack of interest.

*„...at first my husband and children supported me very much in my illness. I am very grateful to them for that, X would buy me flowers and tell me every day that he would love me the same way without my breasts; the children would give me handmade cards. I also received support from my parents, especially from my mother, who took care of my children, cooked, cleaned and helped me a lot when I had no strength. Despite her help, I wasn't doing well on my own and I'm still not doing well. The medicines helped me a little, but it's still bad. I don't know how X will bear it, our marriage will probably fall apart. I can see he's tired of me, there's practically no sex, and when it happens, it's only in the dark so that I don't show these hideous scars. He's going to leave me, and I admire him for being able to hold out for so long anyway. P8*

*„My marriage is practically gone. He is young. He will want children and I can't give them to him. That is why I decided I want a divorce. Not because I stopped loving him, but because I'm not the woman he married. I don't want to waste anybody's life“. P4*

*„He left me with my cancer and a small child in my arms. He did it overnight, saying that he did not want to be troubled by me. Obviously he didn't want to, he couldn't even look at me without my breasts. But it was a good thing that he did, because otherwise I would live in this hypocrisy, don't know for how long.“ P14.*

*„...and he left me anyway, because I couldn't force myself to get undressed in front of him. It's pathetic. For 7 years of our marriage, I thought I had the best husband in the world... until I got ill. He kept pushing me to have sex. Sex was the main theme of every single day, but I just didn't want it, I wasn't ready for it. At first I even tried, against my will, as long as he would leave me*

*alone, but afterwards I felt terrible, I just hated him.“ P13*

*„At first, there was no intimate life at all. I was depressed after amputation. I didn't even want to think about sex. It took me a long time to get over it and not to be ashamed to show my stump, to take my clothes off. I was afraid that he wouldn't accept it. But he behaved as if nothing had changed, he didn't pay any attention to it at all. He never made me feel that he didn't like me. Now I can even have a laugh about it, I just take off my artificial limb and we're done.“ P2*

Research shows that the changes in intimate life were caused by both the occurring depression and anxiety disorders, as well as total atrophy of libido. Female respondents indicated shame of getting undressed; loss of sense of sexual attractiveness; fear of pain (after gynecological procedures). Additionally, there were concerns about the inability to have sex; to plan and give birth to a child. The interviewed also raised the problem of doctors skipping the problems of intimacy and sexuality. The lack of sex and the resulting conflicts became the main reasons for the break-up of 3 marriages; 2 out of 3 divorced women were left during the period of treatment. The women who stated that they are now in separation seem to consider the termination of the marriage in the near future. Men were not very eager to talk about their sexuality, the answers were usually very casual and vague and most of them did not talk about any problems. They were unlikely to have had sexual intercourse during the time of illness, but this was not a reason for growing conflicts. As mentioned in the previous interviews with the respondents, it can be concluded that during their illness men received more support from their wives than women from their husbands.

## Discussion

Thanks to early diagnosis, personalized treatment and the use of modern technologies, cancer has now changed its status from incurable to treatable or chronic. Medical personnel, using military language fight against the disease and against the complications of treatment and are focused on the „here and now“ during oncological therapy trying to guarantee the patient the best quality of life at the time of anticancer therapy. The most important goal in many such situations

is to survive. The fight is to be won. The cancer is to be defeated. How will this process affect patient's life after the treatment is completed? Sometimes this question is not really taken into account. Cancer is such a strong condition that positive emotions can be hard to identify. Uncertainty about the prognosis is evident despite, for example, good epidemiological data on the survivability of people with a particular location of the cancerous lesion and the diagnosed stage of the disease and prognosis.

Recognizing the risks associated with past cancer, EORTC already organized a conference in 2012 at which specialists from various disciplines, eg. clinicians, researchers, social workers, financiers, politicians and patients, discussed the research and health cooperation in the field of cancer survivorship and positive effects of more successful cancer treatment [3].

After completing oncological therapy, convalescents can and will struggle with the late complications of anticancer treatment. Some respondents assumed that a positive end of the treatment was a natural return to so-called „normality“; to pre-illness functioning. In the survey, the respondents specified that the termination of treatment was associated with the completion of tiring procedures; not with joy or relief from the fact of cure. What is more, respondents reported a loss of sense of security connected with the loss of their social role of being the „patient“. Then they were the subject of all activities, most probably feeling settled and confident, able to move safely in their „patient's“ world; although that world offered them a sense of lingering doubt and horror.

Medical personnel are not properly prepared to deal with convalescents. In their study, Lester *et al.* indicate that oncology nurses did not have sufficient knowledge of planning the survivorship care [4]. There is a need for education. In Poland, this aspect still requires further clarification of approaches in cooperation with nurses of various specialties who the patients and their families may contact at various stages of their lives. That need is also confirmed by the fact that most respondents have not yet come to terms with the changes caused by the mutilating surgical procedure. There is interrelation between the young age and mental and adaptive difficulties. There are no comprehensive proposals for the pa-

tient and their loved ones, which could aim to prepare them for life after the treatment [5,6].

Cognitive-behavioral therapy may become an essential part of the patient's treatment, still during illness. Working with beliefs, healthy semantics, and above all acquiring skills to establish a recovery plan and specific tasks for specific time spans, can help significantly in the post-treatment phase. This therapy does not let you lose as a happy life, even if ending with untimely death is also a win [7]. Both, the support of the family and the support of the therapeutic team have a positive impact on shaping active strategies that will help cope with cancer. The most expected type of support in the conducted research is emotional support. What patients await from the members of the therapeutic team, is informational (85% of respondents) and psychological support (45% of the respondents clearly expressed their desire for permanent psychological care).

## Conclusions

Such qualitative research, thanks to its methodology, allows for a deeper analysis of health situations and also for direct identification of the needs, problems and opinions of the patients after the completion of oncological treatment. The research group consisted of 20 respondents which limits the possibility of formulating generalized conclusions, but indicates various directions of possible improvement and, most importantly, shows how thinking about cancer can be changed. The care extended over an oncological patient and their family should be performed not only by specialists in oncology (nurses, doctors, psychologists), but also supported by systemic solutions. It should be multidisciplinary and holistic care at every stage of the healing process.

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# Socio-Psychological Impacts of Terminal Illness on Patients and their Spousal Relationship

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## Abstract:

This phenomenological study was conducted to explore the impacts of terminal illness on patients and familial relationships of couples in Pakhtun society. 36 terminally ill patients selected purposively were interviewed separately (24 male & 12 female patients) by the way of open-ended questions. Numerous themes were extracted following verbatim transcripts. All the participants explained the impacts of terminal illness on their social lives and the positive and negative aspects of their spousal relationship. Depression, anger and desperation were apparent in the terminal patients. Similarly bitterness, guilt, persistent sadness and loss were common in the patients and alternatively in their partners as explained by the patients. This research highlights a distinct viewpoint on the damaging influences which terminal illness can have on the marital relationship. However it also recommends how to deal the situation

in a positive manner by making adjustments required by the concerned disease. The findings indicate that social scientists need to confess and reply to the incredible psycho-social impacts that serious illnesses and related medical procedures can have on the patients and their families even in this modern era of advance technology. Advance social and psychotherapeutic techniques and socio-psychological support of partners can assist such patients to live with a positive life style till the end.

## Background of the Study

Terminal illness is a life limiting condition which carries a high risk of mortality with irreversible decline and expected survival in terms of months or less (Hui *et al.*, 2014). However, technological advancement in the field of medicine has helped people to live with terminal illness for a prolonged time hence such patients need to adapt themselves with multiple physical and social complications as the disease process moves on (Altschuler, 1997). Similarly it also affects the spouse of the patient and the relationship between the two as explained by Sohlman (2004) that various aspects of the relationship like: communication; values; beliefs; socioeconomic relations are heavily influenced. Healthier relationship between partners which has developed before the commencement of the severity of the illness is affected up to a larger extent as one partner become dependent on the other socially and economically. This phenomenological research is first of its nature which is aimed at investigating the Pakhtun community for socio-psychological impacts of terminal illness on patients as well as on their spousal relations.

## Statement of the Problem

The intended objective of this study was to explore the impact of terminal illness on the patients and their spousal relationships. The reason this study is considerable is that there is a deficiency of knowledge about the phenomenological influence of mortal disease on the patients and spousal relationships with psychosocial consequences. We assumed that the psychosocial assistance from the spouse would facilitate and minimize the severity of the terminal illness although the disease would have substantial physical impacts on the patient.

## Objective of the Study

The study is based solely on the aim to assess the socio-psychological impacts of terminal illness on the patients and their spousal relationships

## Literature Review

Earlier than 1960, the only option for terminally ill patients was a quicker and peaceful death as due to inadequate medical technology prolonging of life was not possible. Belding Scribner, an influential nephrologist clarified that “as long as the struggle for survival was the main issue, emotional and social problems were ignored”. This statement led researchers to focus patients for social, psychological and spiritual aspects of terminal illness in their studies (Levy 1996). 64 terminally ill patients were studied by Allen (2003); different stressors were identified and ranked. Fatigue, physical limitations and social maladjustment were recognized as the 3 uppermost stressors. These 3 were followed by psychosocial stressors like an isolated social life and uncertain future. Among the terminally ill population, anxiety and depression are well documented phenomena (Burton *et al.* 2004) however, due to methodological issues the authentic prevalence is not clear.

A great deal of the research on the issue of terminal illness has focused on: treatment; nursing care, palliative care; issues of euthanasia; only a few have looked into the familial relationships. In this regard, Anthony (2000) highlighted familial aspects of terminal illness explaining role, changes in life style and spousal affiliation. Furthermore such patients face difficult social circumstances and become dependent on their spouses for maintaining a healthy role in their families (Lowry & Atcherson, 2001). It is found that many such patients shifted responsibility of their care and treatment to their partners once

they are brought home; and only 65% of patients assisted with preparation for their own care (Brown *et al.*, 2006). A research study performed on 40 spouses of terminal cancer patients confirmed that for their own productive life style, majority of spouses were dependent on their patients' satisfaction level (Pevalin & Goldberg, 2003).

Studies confirmed that individual adaptation of a spouse is mostly predicted by a patient's adjustment to terminal illness and hence the marital partnership plays a major role in the care process (Horsburgh *et al.* 1998). Literally a very few researches can be found that have studied the dyad relationship in a single research since generally terminal patients and their spouses are focused separately. For example Lowry & Atcherson's (2001) studied both patients and their spouses in a single research activity proving the existence of insomnia and anxiety in both patients and partners equally just after the declaration of the disease as 'terminal'. Although patients indicated nervousness of their partners they claimed their marriages to be successful and with few troubles. Another study proved that among partners 20% of such patients face depression, sadness, anxiety and stress (King & Crowther, 2004).

Conclusively there is significant difference in the level of depression among terminally ill patients and their spouses. However this conclusion should not be considered as ultimate because a further review of literature indicates that merely 1/3 of terminally ill patients decide to participate in such studies. The current study has focused on data collection from terminally ill patients and alterations in their spousal relationships as revealed through detailed discussion.

## Plan of Work

This study included the participants who were diagnosed as terminally ill at least in the last 6 months. Moreover, participants were required to be married having spouse alive. Patients with acute morbid conditions, unable to communicate and having a history of dementia were excluded. Medical facility chosen for this study was Nawaz Sharif Kidney Hospital situated in district Swat of Khyber Pakhtunkhwa. Following the inclusion criteria 36 terminally ill patients (24 male patients & 12 female patients) were selected for interview (see table. 1).

## Procedure

After approval from the *Advanced Studies and Research Board* (ASRB) University of Malakand, research participants were accessed in person to take part in the study. To protect the identity of the patients, interviews were conducted confidentially. Through separate interviews it was possible to do an open discussion without being influencing others or being influenced by them. Each respondent signed an informed consent before the interview. All the subjects were free to express their views regarding their illness and social relationships. The interviews were audio recorded.

**Table 1** Demographic and Clinical Information of the Respondents

Demographic/ Clinical Information	Male patients (n= 24)	Female patients (n= 12)
Mean age (years):	41.08	35.7
Gender:	61.5%	38.5%
Marital Status:		
Single	0%	0%
Married	100%	100%
Occupation:		
Unskilled	25%	
Professionals	41.6%	8.3%
Housewife	----	25%
Average income (per month):	56 000 PKR	18 000 PKR
Average duration of terminal illness:	1 year	1 year

## Analysis and Discussion

By using the Husserlian phenomenological approach transcripts were analyzed. The Husserlian approach uncovers a sense of human experiences through talking to people who are living with the true experience (LoBiondo-Wood & Haber, 1994). Thus the purpose of the transcript analysis was to reveal the essential character of the lived terminal illness experiences for the patient by 'bracketing' the researcher's preconcep-

tions. As Lubeck & Hubert (2005) explain “The phenomenologist wants to investigate meaning conferring acts which are strictly relative to the specific place, time, circumstances, participants, culture and personal experiences of respondents”. Earlier research has found that verbal samples include valid indices of the person's psychological state in psychiatric and medically unwell groups (Spector, 2000).

To obtain respondents' unprompted experiences, open-ended research questions were designed. To get a real sense out all transcripts were first read twice. After reaching a consensus by the researchers, themes were extracted in accordance with the phenomenon under consideration. To identify the actual meaning of themes some participants were interviewed again for validation of themes. Researchers made sure that results were applicable to the concerned research population.

**Results**

Many noteworthy statements were recognized about the impact of terminal illness on patients' social lives and their dyadic relationships. Table 2 presents examples of significant statements and their originated meanings. A female patient described that significant physical limitations are developed due to tiredness, altered temper and a loss role and authority in the family circle. Some other patients also expressed similar effects, like social limitations and fatigue.

**A. Patients' perspective regarding terminal illness and its impacts**

Patients' responses were analyzed and various themes extracted to highlight the impacts of

terminal illness on their physical and emotional health.

**Theme 1: Uncertainty of health causing anxiety**

Most patients were in doubt about their health security as the minimal positive health status was interrupted by episodes of acute illnesses: *I do not see any hope of a healthy life but somehow I try to recover as soon as possible. The medical staff is surprised over my living. According to them life is capricious and I do agree with them. As I visit the hospital infrequently and watch those patients who are worse off than me, I start fighting my disease again till a next acute episode attacks me. There are infrequent episodes of happiness and sorrow in my life. Now the doctors try to keep me sedated most of the time. This sedation is not helping me that much.*

The relationship between fatigue and terminal illness was described by the patients in detail. This was same for them as well as their partners: *This disease has weakened me a lot. I feel that my lower limbs are not parts of my body anymore. I sit and hardly stand with the help of others. My husband spent most of the day in his shop and when he comes home he has to look after me and the children for hours. This is really a big physical burden for him.*

**Theme 2: Changes in daily life since the beginning of terminal illness**

The relative impacts of terminal illness on patients' lives were discussed by all respondents in detail. Limitations imposed by disease leading to social exclusion was a great concern for all. Due to various physical and medical needs all the

**Table 2** Statements of terminal patients' experiences and their dyadic relationship

Patients' Statement	Extracted Meaning
<p>I It is a surprise for to be still alive....I am not sure when another episode of illness will strike me.</p> <p>II I get absolutely fed up..... why the people in surroundings are changed so quickly and unexpectedly</p> <p>III We are living as a couple for 16 years and we have a good time. Beside minor difference of opinion sometimes we enjoyed a good life together. This illness has made some problems.</p>	<p>I Anxiety was prevalent among patients due to uncertain health conditions</p> <p>II Many unexpected psychological responses were exhibited by the terminally ill patients (including annoyance)</p> <p>III Respondents portrayed positive relationship with their spouses with some signs of hopelessness</p>

time, most patients were unable to go outside their residence. This situation was faced by all the patients: *We want to visit various venues, places and relatives but we need to carry various medical equipment and take medicines with us. This is troublesome not letting us to move freely. This illness has changed our normal life.*

Some patients explained changes in earnings due to inability to perform their job. This has led to many life-style changes. Some changed their residences facing a new physical environment and neighborhood: *This was our dream to live in a house owned by us, and luckily we built our own house. We were really happy there. Then I got ill. Now we are living again in a rental house near the hospital because traveling from far away is difficult for all of us. However, living near a medical facility is also an advantage.*

Almost all of the patients highlighted the harmful impacts of terminal illness, for example financial changes, changes in role, and social exclusion. Among these, social isolation was a major concern as explained by patients: *I used to recite the Holy Quran daily and it brings mental satisfaction to me. I do it in a separate place. I do not want to meet people frequently as I used to do it in the recent past.*

### **Theme 3: Severity of illness and negative emotional responses**

Terminal illness and related medical procedures imposed some physical, social and psychological restrictions on patients. These limitations led to some emotional responses including depression, anger and daydreaming ideas. Some patients wished to enjoy a disease free life for a week and take care of their children. Some patients refused to cope with the impact of the disease and did not consider themselves as terminally ill: *My disease is not the fatal one. I have seen patients on YouTube who have undergone liver transplant successfully. I hope I will be better soon.*

Many patients did not describe their disease name specifically but called it as 'it' in an angry unconcerned mood while some were living in fantasy of life without disease. This was an idealistic expectation: *I will get better soon InshAllah (if Allah Wills). I have seen some patients who were severely ill and were treated get healthy. I believe in miracles.*

Some patients were angry because terminal illness affected their social and family roles i.e. from independence to dependence. Answers were full of anger and annoyance: *I am truly frustrated. I was a fine wood worker. I got ill at a younger age. Now I cannot join my friends company. This has been happening for the last 10 months.*

## **B. Patients' perspective regarding terminal illness and its impacts on spousal relationships**

Following data analysis, patients' opinions regarding the effects of terminal illness on spouse relationships were organized and represented in the form of separate themes.

### **Theme 1: Constructive aspects of patients' marital relationships**

Respondents expressed optimistic views regarding spousal relationship. Negative remarks were less common among their statements. Most patients were in their marital relationship for more than 10 years. All respondents explained the role of their spouses with respect, sympathy and appreciation. Talking about her husband an interviewee was a bit shy: *We always took care of one another for the last 14 years since our marriage. Now after I got ill, my husband never let himself to be careless or bored.*

Subjects also talked about the personality and nature of their spouses. According to them some were solicitous and soft-hearted, while others were too much worried for them. Some showed a friendly and cordial behavior whereas some were restless. The spousal relationship of many patients was based on intimacy and respect: *Since I got ill, the only major source of my assistance is my wife because she manages those aspects of my illness which cannot be performed normally by someone else.*

Patients described the role of their partners as positive and cooperative: courage, love, care and friendliness were the words used by patients during the interview. Both male and female patients praised the role of their partner.

### **Theme 2: Thoughts of liability towards the spouse**

Some subjects expressed their feelings telling that their severity of illness has caused physical

and psychological burdens for their partners: *He (my husband) performs several tasks at a time like his job, caring me and also managing household activities sometimes.*

Respondents also showed worry about the health of their spouses. This is due to the extra workload faced by partners during the care and treatment process. They also appreciated the partners for the provision of physical and psychological support: *She (My Wife) waits for me all the time before I reach home. She calls me frequently when I am not at home. She never felt her tiredness to me but I can feel how tough her life is.*

### **Theme 3: Weary response of spouse towards patients**

Some patients explained the altered behavior of spouses and their changing attitude towards them. Their partners seemed to be overtired and ignoring them sometimes: *After commencement of my illness as serious, my wife was extra careful initially. She managed both me and the children very well but with the passage of time my needs were too many to be managed. I felt that she is exhausted to manage everything all the time. I think this is normal for any human being.*

Moreover the ambiguous gratitude of the spouse was explained by patients: *Sometimes my husband portrays me as self-centered, demanding and impatient. This is often true when I am in pain or need an immediate help.*

### **Theme 4: Spousal relationship failure**

Many patients explained loss of physical intimacy and partnership due to terminal illness: *It has badly influenced our marital relationship. We both remain too much exhausted to perform daily routines. We are busy handling the disease and related complications. It has caused physical and psychological troubles which do not let us to take care of our marital adjustments.*

The expressions of patients were such that they thought their life has come to an end since the onset of terminal illness because they used past tense during the interview discussion.

## **Discussion**

This research study focused to explore the impacts of terminal illness on patients and the dyadic relationship they have with their spouses. The results revealed a complex interrelation be-

tween terminal illness and anxiety, depression, role alteration and emotional disturbances. Although the data showed a combination of both positive and negative reactions of the respondents towards their disease and health status, majority expressed depressing features of terminal condition. This is probably due to: severity of illness; co-morbidities; low socioeconomic status; disorganized healthcare systems. Alternatively it could be perceived that terminal illness is itself a negative life event. Such illness leads to negative features like: limited social interaction; irritation; anxiety; other key variations in life-style.

During the interview process it was eminent that patients were exhausted all the time and unable to do anything and were tired. Our findings: depression; anxiety; social exclusion; insecurity regarding the future were similar in nature as found in other research by the Council on Scientific Affairs, American Medical Association (1996). Terminal illness is a combination of fatal attacks, unpredictable episodes of acute illnesses as well as stability. This complex scenario of health leads patients towards psychological and spiritual adjustments where they start believing in fate and miracles.

All the subjects expressed their views regarding the impact of terminal illness on spousal relationship. Patients expressed major life-style changes since the commencement of their illness. Some of their concerns were failure to do work, to travel and to move to another place with their spouses. Hinton (1994) also found some results which highlight similar family concerns. Some patients explained that social isolation, loneliness and prolonged treatment procedures have affected marital relationship and were their most important worries. Terminal illness and related complex treatment protocols have pushed patients to face sadness, anger, and fatigue.

Accordingly their spouses were also regularly resentful, exhausted and nervous. Unexpectedly, some patients explained their spousal connection as very constructive, lovely, and full of care. The impacts of terminal illness on marital relationships were expected to be complex, negative and uncertain due to associated co-morbidities and social detachment. However, this study found that it is not true in every case. Probable conclusion of this might be that they had a consistent marital relationship before the onset of terminal illness.

The role of the spouse in supporting health of their partners was acknowledged by the subjects. They admitted that without help of their spouse treatment and care would be impossible. However, the loss of physical intimacy, inequality in partnership and dependence were indicated as hurtful results.

Some limitations of this research were different in economic and educational status of the samples. Some mystifying effects might be due to the low socioeconomic status and not the disease. Moreover, the use of an audio recorder might have an artificial impact on the expressions of the respondents.

## Conclusion

Following a phenomenological plan, this research study has described the experiences of terminally ill patients and the impacts of their disease on them and their spousal relationship. Life with terminal conditions is fearsome for both patients and their family members especially their partners. The findings show similar types of concerns for almost all the patients i.e. sadness, anger, hopelessness, etc. Similarly the marital partnership has been affected about which the respondents expressed various positive and negative consequences.

Improvement in the socioeconomic status, provision of advance medical facilities can help to minimize patient suffering. Moreover, familial socio-psychological support and positive dyad relationship can assist such patients to live with a quality life till the end. The suggestions for the sociologists and psychologists are that they need to identify and answer to the incredible psychosocial impacts that serious illnesses and related medical procedures can have on the patients and their families in a modern era of advance technology.

This research study provides a platform to the researchers to explore some other aspects of terminal illness. These may include alteration in religious spirituality, parental relationships and economic impacts.

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# The Well-being of Children and Young People: The Context of Social Services from the Perspective of the Capability Approach

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## Abstract:

**Objective:** The aim of this article is to understand how social services contribute to the well-being of children and young people who use them.

**Method:** The research study, based on Capability Approach, was done using a mixed-research strategy.

**Participants:** The collection of data took place through 44 in-depth semi-structured interviews with children, young people and their parents/foster parents who use social services in one of the regional capitals of the Czech Republic.

**Results:** Parents at risk underrate their role in loving and caring for their children. Parents at risk are more likely than children

to undervalue education. Social services do not develop youngsters' capability to live a meaningful life.

**Conclusion:** The research has shown that although social services have significant potential to ensure well-being for children and youth, they work primarily in a way that provides clients with basic social functioning in the present, without influencing their future positively.

## Introduction

Ensuring the well-being of children is a central motive of governmental measures related to protecting children and safeguarding their rights. *The United Nations Convention on the Rights of the Child* (The United Nations, 1989) guarantees all children under the age of 18 the observance of their rights and assurance of their best interests (the Czech Republic acceded on 6 February 1991). The state thus becomes the principle guarantor, which, in the spirit of Article 3 of the Convention, "oversees the protection and care necessary for the child's well-being". The Convention has given the child completely new status: the child has become an independent subject of the law, which guarantees respect for the identity of his/her person and the legal right to the assurance of well-being.

Although the notion of child well-being is a common part of legislative practice affecting the work of all those in the area of child protection, its meaning is not absolutely clear, thus leading to a number of difficulties in practice. Various interpretations of child well-being are reflected in diverse concepts of practice, which may pose a certain risk to the social functioning of children and young people.

We believe that reflecting on the concept of child well-being will facilitate at least basic insight into the context of its historical development, which reflects its transformation in the understanding and emphasis that have been attributed to well-being. In brief, the content of child well-being has been significantly shaped in society by the "social indicators movement" and "children's rights movement". The UNICEF initiative has been of great importance for the interpretation of child well-being, and has led to the observation of the situation of children in the world, the assurance of their rights and research into their well-being. Since 1979, when the first such report, *State of the World's Children* (Adamson, 2013), was published, there has been a systematic look at

the situation of children in the world and how they benefit. Almost 4 decades of systematic interest in the well-being of children has also meant a period of conflicting opinions and expert disputes about which indicators are relevant for measuring child well-being, how they should be measured, and what social policy measures should be implemented. Ben-Arieh (2010a; b), one of the most prominent researchers in the field of child well-being, points out, in agreement with Khan & Kamerman (2009), that in the understanding of child welfare, we have moved from the original notion of rescuing poor and suffering children to the current idea of supporting the development of child well-being. This development reflects the fact that the child is seen as a distinct autonomous being who has his/her own physical, psychological, spiritual, cultural and social qualities, all of which need to be developed and supported in the interest of the thriving and flourishing of the child (Ben-Arieh *et al.*, 2014).

Emphasis on the well-being of children has also prompted the need to monitor the prosperity of those children whose life situations require specific attention (Gojova *et al.*, 2020; Glumbikova, 2020; Land, 2000; Selwyn & Briheim-Crookall, 2017; Mydlíková, 2017; Punova, Navratil & Navratilova, 2000). In light of this goal, we focus our attention to a group of children who are in the care of social services. Based on the research, this article should answer the question: ***How is well-being developed in children and young people who use social services?*** In assessing the development of well-being, we refer to the Capability Approach to anchor our theoretical and methodological conceptualization and assess how social services in the selected locality support the development of child well-being.

## Child well-being and the Capability Approach

Nowadays, when examining child well-being, the Capability Approach (CA), developed

by Amartya Sen (1999; 1993) and Martha Nussbaum (Nussbaum, 2000; 2007), has increasingly been gaining attention. The Capability Approach focuses on the conditions, possibilities and capabilities that enable people to live a life of well-being and prosperity. Both authors, who have made a significant contribution to the formulation of the concept of well-being, point out that not every person in society has the same opportunities and freedom of choice to achieve dignified well-being.

Sen's interest in issues of human development and quality of life in the context of existing global inequalities, poverty and famine resulted in the conceptualization of criteria for quality of life and human development, including Human Development Index. The fundamental optics for viewing the functioning of an individual in society include capability, understood as "a varied combination of functioning (ways of being and acting) that a person can achieve. Capability is a set of working vectors reflecting the personal freedom to lead a certain way of life... to choose from possible lives (Sen, 1992). In other words, it is "substantial freedoms that a person uses to lead such a way of life that he/she has reason to appreciate" (Sen, 1999). In Sen's conception, capabilities are perceived as "the ability of an individual to do valuable deeds or to achieve a state of being he/she values" (1993). The decisive factor is, according to Sen, "freedom of choice," which is determined by the structure of the options available to a particular person (1992). In this respect, the notion of capability is essentially a "concept of freedom" reflecting the spectrum of choices that a person has in deciding what kind of life he/she wants to lead (Palovičová, 2011). Different options available to the individual thus lead to different levels of capabilities. These are explained by Sen as the individual peculiarities of individuals, and their cultural and social specificities (1993).

Sen and Nussbaum advocate different approaches to capabilities. Sen's ideas are integral to the participatory development of a person based on the ability of individuals to express and defend, through social dialogue, the minimum degree of capability that would enable such a quality of life that a given society deems as valuable; however, Nussbaum is critical of such an attitude. Her selection of capabilities is

founded more as the fulfillment or non-fulfillment of which is an indicator of the existence or non-existence of capabilities. Nussbaum is critical of Sen's assumption that all individuals have the same opportunities to participate in social dialogue and negotiate capabilities allowing them to live the kind of life they could appreciate. For example, people with disabilities point to the fact that there are always individuals in society who are not able to formulate and promote their own rights (Nussbaum, 2007). In contrast to Sen's approach to capabilities, Nussbaum applies a more analytical attitude based on the need for a fairer approach to people who are unable to rationally participate in creating the conditions for the kind of life they could value. In this respect, she has identified 10 basic capabilities she considers to be the foundation for a dignified human life. They are "a set of basic human claims that create a prerequisite for various ways of life; claims that are contained in the idea of human dignity" (1999; 2007).

In the context of the Capability Approach, human well-being is assessed merely by the degree to which an individual achieves the kind of functioning that he/she values. The assessment of human well-being presupposes a distinction between capabilities and human functioning, with "capability meaning only a real opportunity to achieve social functioning in various areas" (Sen *et al.*, 1993). Social functioning itself is a concrete result that the individual has achieved. Palovicova (2011) states that "the difference between capabilities and functioning is, therefore, the difference between the possibility to achieve social functioning and its actual achievement; between the potential and the outcome."

Although Sen and Nussbaum choose different ways of promoting well-being, they agree that society should create fair conditions (for capability) for all, which presupposes taking into account the unique conditions of individuals and their cultural and social contexts. Because of the way the CA is conceptualized, it opens up space for analyzing the physical opportunities that people encounter and their freedoms for achieving a valued way of functioning, as well as making it possible to work with the needs, desires and feelings of individuals. The multi-dimensional character of CA allows us to track several factors simultaneously (Alkire, 2008; Deneulin, 2002).

Nussbaum's endeavor to have a fair approach to providing conditions for a dignified life, especially for those who have difficulty accessing this, has strong resonance in consideration to child well-being. Arising from a constructivist perspective, the CA approach has thus become one of the pillars of the "conceptual frameworks for understanding the well-being of children" (Biggeri, 2017; Biggeri *et al.*, 2007; Fegter & Richter, 2014; Navratilova, 2018). This has contributed to the fact that the methodological features of this approach can respond to changes in the way children are perceived which has occurred in the social sciences. Fegter & Richter (2014) characterize these changes in 3 points: 1) the child has become the subject of separate analysis, rather than merely a part of family analysis; 2) there is an increasing focus on the need to explore the diverse areas of children's lives that are important to their everyday life; 3) children are increasingly considered to be "experts on their own lives".

Fundamental shifts in perceptions on children and childhood have also had a significant impact on methodology. In contrast to the previous adult-centered perspective applied in the analysis of child well-being, attention has shifted directly to children. Children themselves and their view on how they see their possibilities to realize their own life are now at the heart of the analyses. As such, an autonomous space has opened up for children allowing them to freely and actively participate in shaping their own lives. The child is seen as a distinct social actor; to understand him/her, it is necessary to explore his/her own experiences and ideas (Navrátil, 2019). The Capability Approach allows the understanding of a child's reality not only on his/her individual level, but also takes into account the social context. It is especially the network of relationships between the possibilities that children have and their vision of how they would like to live that can capture the quality of their functioning, or the level of their well-being. This makes it possible to gain a more accurate image of what is important for the child's life from his/her point of view.

## Method and study characteristics

An empirical survey was carried out using a mixed research strategy of semi-structured in-

terviews. We created interview scenarios for children and adolescents and their parents / foster parents based on Nussbaum's list of 10 capabilities that are a prerequisite for a dignified life: (1) life; (2) bodily health; (3) bodily integrity; (4) senses, imagination and thought; (5) emotions; (6) practical reason; (7) affiliation; (8) other species; (9) play; (10) control over one's environment [13]. This list of capabilities was updated on the basis of the work of Biggeri *et al.* (2007) which focuses on the study of capabilities in children.

With regard to finding answers to the main research question (*How is well-being developed in children and young people who use social services?*), the interview scenario covered 4 main areas that were focused on determining the following: **1) child capabilities; 2) the achieved functioning within the individual dimensions of capability; 3) the impact of the service on the individual dimensions of capability; 4) which aspects of capability the project should prioritize.** This scenario enabled the children and young people to determine the most appropriate dimensions of capability and to assess their functioning in light of their ideas of how they would like their life to be. At the same time, it also made it possible to see to what extent the parents consider social services as creating an environment that promotes well-being for their child.

1<sup>st</sup>, from the point of view of determining the capabilities of children, we identified the following: "*What are the most important opportunities that children / young people should have during their lives?*" The aim of this question is to find which capabilities (i. e. opportunities) are relevant here, without us limiting the possible responses by a predefined range of options. When the child mentioned a capability that was not previously identified by a researcher, we added the response to the list. When the child mentioned a capability that was already listed, the response was noted. As such, the children directly participated in the formulation of the questionnaire. This phase of interviewing allowed us to conceptualize and identify various capability dimensions.

The 2<sup>nd</sup> phase of the research was focused on the functioning of the individual capability dimensions that they spoke about in the 1st phase. The children and young people were asked to

evaluate every capability based on their experience. For example, in regards to the "health" capability, we asked, "*Have you been feeling healthy lately?*" The result was also noted by the children according to the Lickert scale (1 – lacking; 10 – full health).

In the 3rd phase, we asked the children about what impact the social services had on their capabilities. For this reason, we asked (e.g. in regards to the health capability) "*Do you think that the social services you use affect your health or the possibility of living in a healthy way?*" The aim of this question was to measure the impact of social services on each identified capability dimension from the subjective view of the children. This question evaluates the expanding or contracting of the capability.

In the 4<sup>th</sup> last phase of the research, the children were asked what capabilities should be given more attention in social service. Each of the children was questioned about their preferences. The aim is to identify which capabilities the service should pay most attention to. For this reason, we asked, "*Which areas of life should the social service pay more attention to in the future?*"

Before the implementation of the research, interviewers were trained on the basis of a specially created Interviewer's Manual which included an interview script and remarks sheet. The length of the interview, including filling in of the remarks sheet, ranged from 30-60 minutes, depending on various circumstances, especially the respondent's age; the interview environment; the motivation of the respondent. The conversations were recorded on a Dictaphone, transcribed and then qualitatively interpreted. Selected interview information was also transferred to a remarks sheet containing the list of capabilities, including new ones, so as to make it possible to quantify them all. Scaling techniques have also been used within this strategy. The collected data were processed using IBM SPSS Statistics.

The selection of respondents took place in cooperation with social services organizations thus allowing us to collect data directly from the organization. In total, there were 28 in-depth semi-structured interviews with children and young people up to the age of 22. The average age of the interviewed children and youth was 15.4 years, with the ages ranging from 11-22 years.

For the youth over the age of 18, we encountered some individuals who continue to make use of social services for youth, despite being over the age limit (of 18).

At the same time, however, we also considered it essential to speak with their parents/foster parents, who have experience with social services and who naturally could evaluate the impact of these services on the children's lives. We conducted 16 interviews with these parents/foster parents: 45% of which were men; 55% women. Average age of the interviewed parents was 44.6 years. The youngest parent was 25; the oldest 70 (this was the case of a foster grandmother). All participants provided informed verbal consent with their participation in our research.

## Results

In the following section, we present the basic empirical findings related to the evaluation of 4 of the researched areas of capability.

### Main areas of potential (opportunities and possibilities)

Table 1 shows the perspective of children and their parents on what opportunities they consider valuable and essential in order for children to be able to thrive. In order to secure the well-being of their children, parents see as the most important areas: *the presence of loving and caring parents (or surrogate parents), and opportunities for learning and health (both 56% of the parents)*. A slightly smaller but significant percentage of all the parents (50%) identified the area of *safety*; over 77% of all respondents (children and parents together) agreed with this point.

It seems that the parents want their children to enjoy the commonly held values of *health, safety, a family setting and learning opportunities*, which are considered in this society to be prerequisites for a successful life. Parents believe that the following are also important for their children: *having good relationships (44%), an open future (38%), and to have a life free from bullying (31%)*.

From the point of view of relationships, it is evident that parents prefer their children to have close family relationships, that is, between child, parents and siblings. Other (more distant) family relationships, and those with friends or within the community are of lower priority.

**Table 1** The importance of individual areas of life from the perspective of children & parents

Areas of life	Child/ Adolescent		Parent	
	Count	%	Count	%
Health	3	10.7	9	56.3
Loving parents	25	89.3	9	56.3
Siblings	7	25.0	4	25.0
Relatives	5	18.5	3	18.8
Friends	16	57.1	3	18.8
To be feeling fine	3	11.1	5	31.3
Safety/security	3	10.7	8	50.0
Good relationships	12	42.9	7	43.8
Having personal opinions	2	7.1	1	6.3
Chance to learn new things	4	14.3	9	56.3
No bullying or exploitation	3	10.7	5	31.3
Nice clean environment	3	10.7	4	25.0
Fun	4	14.3	2	12.5
Respect	3	10.7	4	25.0
Spirituality	1	3.6	1	6.3
Enough time	3	10.7	2	12.5
Goals	3	10.7	3	18.8
Going where I want	3	10.7	3	18.8
Orientation in life	-	-	4	25.0
Open future	4	14.3	6	37.5
Money	5	17.9	1	6.3
School	4	14.3	1	6.3
Work	4	14.3	2	12.5
Accommodation	3	10.7	-	-

It is interesting that parents do not place emphasis on areas that are potential sources of creativity development for their children: such as the ability to express their opinions; have their own goals in life; or form relationships with friends. It seems that parents remain in their parenting “guardian” role and consider the needs of the child only from their point of view. It is clear that the application of an adult-oriented perspective suppresses those areas of children's lives that are important to their development and future.

We analyzed the same question exclusively from the point of view of the interviewed children and young people who use social services

and social work services in the city of Brno. The research revealed differences in the viewpoints of the parents and children. The children's views were not so different overall; however, there are some noteworthy differences.

The children and young people assess the importance of the presence of loving and caring parents even more often than the parents. Almost 90% of them spontaneously stated that the presence of affectionate and caring parents is a very important condition for their well-being. Overall, children and youth are particularly in need of social relationships to be satisfied. Among the most-described conditions for a good life, there are also relations with *friends* (57%), good *relationships in general* (43%) and relationships with *siblings* (25%). In comparison to the parents, some areas of life are not considered as crucial by the children: security (11%); learning (14%); respect (11%); open future (14%). The question is to what extent certain factors play a role in the children's evaluation; for example, they may feel satiated in terms of security and learning, while certain points may be completely irrelevant or even unimaginable for them for the time being.

The research data show the differences between parents' and their children's views of what is important for children to prosper. We consider empirical mapping of these differences to be crucial to confirming the importance of including the perspective of children in a study of child well-being.

### Assessing the State of Conditions of Life

In our research, we also focused on assessing the current state of conditions for child well-being. Table 2 shows the average assessment of the state of conditions for child well-being in individual areas of life. The table contains a comparison between the evaluations of the children/youth and parents. We particularly point to those areas where there are noticeable differences between them. The respondents used ratings from 1 to 10, where 1 is unsatisfactory and 10 is the best possible situation.

Of the areas that were actively evaluated by children, the worst ranked item was Open Future, which rated an average of 3.0 points. Unfortunately, the item Support was also rated 3.0 by children. This item represents formal sources and places of support where children and youth can

**Table 2** State of the individual areas of life from the viewpoints of the children and parents

Areas of life	Child Mean	Parent Mean
Health	9.33	9.10
Loving parents	8.48	8.22
Siblings	9.14	10.00
Relatives	9.00	9.67
Friends	8.50	7.33
To be feeling fine	9.33	7.40
Safety/security	7.33	5.57
Good Relationships	8.33	7.43
Having personal opinions	7.50	8.00
Chance to learn new things	4.67	6.50
No bullying or exploitation	10.00	6.75
Nice clean environment	9.00	10.00
Fun	6.00	7.00
Respect	10.00	10.00
Spirituality	-	9.00
Community	9.00	7.50
Enough time	7.67	8.67
Goals	7.67	5.33
Going where I want	-	6.75
Orientation in life	8.50	7.00
Open future	3.00	-
Money	8.50	8.00
Support	3.00	8.00
School	8.00	10.00
Work	9.25	10.00
Accommodation	10.00	-
Money	7.50	7.33
Special Education	10.00	-
Decent education	-	10.00
Social worker	10.00	-

turn when in need. It is not clear whether this reflects an inadequacy in their knowledge of available possibilities, or whether there is an actual absence of support. In either case, however, this is a serious finding that requires action. The overall average of the status of Support (including the rating by parents) was higher. Thus, parents assess the possibilities of formal support more positively. It is likely that they have a positive expe-

rience with the provision of this support.

The item regarding a chance to learn new things was rated somewhat better. Nevertheless, the state of this condition was assessed by children and young people as below average (4.67). Even here, children express a more critical assessment than that of their parents, who rated it at 6.50 on average. In contrast, the research shows that children rate various items less critically than their parents: for example: their safety; their idea of feeling fine; their feeling of belonging in the community; social services helping them achieve their goals. From the point of view of children, it is evident that social services are not only a source of safety and protection, but also development. It is interesting, however, that children are unable to associate this support to ideas about their future. It seems that children primarily appreciate their present state without linking it to their future.

There is a serious gap in the ways that parents/foster parents and children/youth assess the areas of life. This shows that understanding the child as a client should also be sought in the effort to design adequate services; not just the opinions and experiences of parents are important (but neither should they be underestimated). It is evident that we need to talk openly with children about their future and explicitly about how to achieve a successful future.

### **The impact of services on the state of opportunities for children from the perspective of children and parents**

In the research, we looked at how respondents perceive the impact of social services and social work services on individual areas of life that are important for the well-being of children and youth. Table 3 shows the average ratings of service impact according to the respondents' ratings, especially the comparisons between the parents and children. As in the previous case, the respondents worked with a scale of 1-10, with a score of 1 being a bad influence and an evaluation of 10 being the best possible impact.

In general, children and young people who have participated in the research evaluate the benefits of the services mainly on the positive side of the scale. Values exceeding 5 can be considered as an assessment of benefit. The children negatively evaluated only the area of finance (av-

**Table 3** The impact of services on individual areas of life from the perspective of children and parents

Areas of life	Child Mean	Parent Mean
Health	5.70	5.86
Loving parents	6.22	7.50
Siblings	8.00	7.25
Relatives	6.00	7.33
Friends	8.13	6.67
To be feeling fine	8.00	8.00
Safety/security	9.67	9.29
Good relationships	8.10	9.00
Express personal opinions	9.00	9.00
Chance to learn new things	0.75	8.56
No bullying or exploitation	6.00	7.80
Nice clean environment	9.33	9.50
Fun	8.75	7.0
Respect	6.33	9.25
Spirituality	7.00	10.00
Community	-	9.00
Enough time	5.33	10.00
Goals	7.33	10.00
Going where I want	8.33	7.33
Orientation in life	-	8.75
Open future	7.00	8.00
Money	4.00	6.50
Support	10.00	-
School	7.50	10.00
Work/Job	8.25	7.50
Accommodation	7.00	-
Free-time activities	-	3.00
Decent education	6.00	10.00

erage 4). However, this result can be understood as meaning that social services do not allow young people to earn money.

Services are valued for their contribution as a source of support (average rating 10). They are perceived by children to provide safety and security (9.67), as well as a nice clean environment (9.33). The services are also highly valued for providing opportunities for expressing and cultivating personal opinions (9), as well as creating and offering leisure time facilities (fun 8.75). The

services expand their clients' possibilities in the area of spatial mobility (8.33) and increase their chances of obtaining a job (8.25). Children also perceive that the services increase their possibilities for an open future (7). It is evident that the potential of social services to help provide a better future for children is great and that children also perceive it. It is a challenge for social services to exploit this potential, because the unfortunate data showing little hope of an open future for children in the care of social services may point to unused resources. It is also worth mentioning that, according to children's assessments, the services are not able to influence the provision of loving and caring parents. The average rating in this area is 6.22. We believe that it would be worthwhile to consider whether and how the focus of services can be developed and strengthened in the future. It is evident that the development of parental competences of the parents/foster parents would be appreciated by the children in the study.

From the perspective of parents there is a better evaluation primarily in the area of relationships, especially between themselves and their children, and between relatives and children. Compared to children, parents give a lower rating to the impact of services on sibling and friend relationships. Compared to children, parents give a significantly higher rating to the amount of free time. This difference is worth noting because, as other research shows, the nature of free-time activities affects children's well-being (The Children's Society, 2017).

### The development of social services in terms of capabilities

In this section, we asked about which conditions of life should be given more attention in the context of social services and social work services. We asked children and parents about their preferences for future service delivery. The aim is to identify the most important conditions that service providers should pay increased attention to. The areas of life are judged on a scale of 1-10, where 1 has the least importance for service development and 10 has maximum importance.

The average values, which respondents assigned according to the importance of individual areas of life for service development, are presented as a comparison between parents and chil-

**Table 4** Development of services with respect to individual areas of life from the perspective of children and parents

Areas of life	Child Mean	Parent Mean
Health	4.50	4.22
Loving parents	6.40	5.11
Siblings	5.00	3.75
Relatives	5.67	4.33
Friends	7.43	6.67
To be feeling fine	8.33	5.25
Safety/security	10.00	7.29
Good relationships	6.80	6.14
Having personal opinions	6.50	9.00
Chance to learn new things	7.50	7.89
No bullying or exploitation	3.67	6.40
Nice clean environment	4.67	10.00
Fun	7.50	5.50
Respect	5.33	4.75
Spirituality	5.00	1.00
Community	-	2.00
Enough time	6.00	1.00
Goals	5.33	7.00
Going where I want	9.50	9.67
Orientation in life	-	7.75
Open future	6.00	9.80
Money	5.80	8.00
Support	5.00	-
School	2.00	10.00
Work	4.33	9.00
Accommodation	7.33	-
Car	5.00	-
Education	-	5.00
Free-time activities	-	4.00
Decent education	-	10.00

dren/youth who participated in the interviews (Table 4).

In terms of future service development, the priorities for children and youth included: safety/security (average 10); spatial mobility (9.5); emotional well-being (8.33); development of knowledge and skills (7.5); leisure-time activities. It is worth noting that parents' ratings for safety/security and mental/emotional well-being

appear to be less significant (7.29). However, the views of children here reflect some criticism.

Another 5 areas that children and young people proposed as important for the future targeting of services range in average values from 6.04 to 7.43. This area has unambiguously subjective weight given to the topics; however, the data should also be taken into account in future strategies for service development. The topics include: relationships with friends (average value 7.43); the issue of temporary/permanent housing (7.33); the topic of relationships (6.80); the area of expression and cultivation of personal opinions (6.5); as well as the sphere of support for parental competence (6.04).

When we look at the priorities for service development with respect to the opinions of parents, other important topics appear. The following topics were in the highest positions: a nice clean environment (average 10); raising children to be decent (10); with emphasis on services helping to provide an open future for the children (9,80); as well as a focus on helping children/youth to gain good orientation in life (7,75). It is interesting that in contrast to parents' high rating, children themselves support the development of services in the area of an open future at a value of 6, which is slightly higher than average.

## Discussion

The main objective of this article was to understand to what extent social services enable children and young people to improve their well-being. The research, anchored in the theory of capability, not only examines whether social services create conditions for children to prosper, but also shows an image of what children themselves consider as important for achieving their own well-being. In order to better understand what children in the care of social services need, we are taking into consideration results obtained and their interpretations in the context of other research studies involving subjective measurement of child well-being (Selwyn & Briheim-Crookall, 2017; The Children's Society, 2017).

These studies, like ours, have shown the crucial role of relationships in children's lives. The success of children and young people in relationships with peers and others is crucial. According to research (Richardson *et al.*, 2008; Selwyn &

Briheim-Crookall, 2017; Vysloužilová & Navrátil, 2019), these relationships influence children in the perception of themselves as social actors and generally affect the level of their life satisfaction. For children in our group, this means primarily the relationships with parents, whether biological or surrogate. This is closely followed by relationships with friends. For children, the importance of relationships with others is greater than for their parents, although even the parents consider them to be crucial.

In the context of relationships and their fundamental position in children's lives, we should pay increased attention to their development. A comparative study of the Children's Society (The Children's Society, 2017) has produced strong evidence that the quality of these relationships is deteriorating. From 2009 to 2015, there was a decline noted in the level of happiness in relationships with friends and in life generally. Although this trend was observed in British children and young people, an annual comparative study by UNICEF on the situation of children in the world also reflects this fact. For the Czech Republic, this trend is even more pronounced. According to the above UNICEF study, conducted in April 2013, the Czech Republic has the lowest values of all the countries of Central and Eastern Europe in the quality of children's relations (26<sup>th</sup> place). Only 56% of Czech children consider their classmates to be "nice and considerate". This rating is one of the lowest in the developed world (Adamson, 2013). In this respect, it seems essential to create within the framework of social services conditions that promote good relations and at the same time prevent risky forms of relationship development. This does not concern only the prevention of bullying, but mainly the prevention of arguing and fighting among children. According to this UNICEF report, Czech children are among the highest in the level of conflict among peers.

A more positive point is that social services are seen as a means for helping children and youth to become incorporated into a network of relationships. However, a certain risk can be seen in the fact that social services do not focus on the development of these relationships. The possibility for building interpersonal relationships has arisen as a natural consequence of the fact that social services are, used by other people through

whom the children and youth are drawn into a network of relationships. An active approach to developing this capability could in many ways result in increased success in children's lives. For example, the results of a research study (Selwyn & Briheim-Crookall, 2017) have shown that in order to fulfill the well-being of children in care, it is crucial for the child to have at least one key adult available. Thanks to such a relationship, many skills and abilities develop that are important for the child to mature, and are prerequisites for a successful life.

Perhaps the most serious observation brought about by this research is the perceived lack of hope for the future of the children using social services. The results of the research have shown that skepticism regarding the child's future outweighs optimism and hope. The research findings show that children and young people in social services do perceive that these services affect their future; however, they do not expect them to be a means to help contribute to a promising future.

It has often been shown that hope is an important part of such life prospects, enabling people to actively participate in personal and social life (Matejcek, 1999). It is interesting that the studies in the UK (Selwyn & Briheim-Crookall, 2017) are generally consistent with the results of our studies, although there is one fundamental difference: the British children living in surrogate family care, unlike the Czech children, see hope for the future. This is an alarming fact that cannot be easily resolved and deserves proper attention. These results represent a great challenge for social workers working with these children. It is evident that the mere factual existence of certain capabilities is no guarantee that children will be able to use them; that they will be able to perceive certain potential as meaningful for turning it into a result.

From the point of view of capability approaches, through which we view the well-being of children, it seems to be appropriate to develop services that, instead of merely ensuring material well-being, are consciously aimed at developing the physical, mental, emotional, spiritual, cultural and social characteristics of children, as essential prerequisites for the development and promotion of their well-being. A prerequisite for this development of social services is the education of so-

cial workers, which develops their professionalism (Navratilova & Navratil, 2020; Punova, 2019; 2020)

## Conclusion

In this research on the prosperity of children using social care services, we have used a research tool based on the Capability Approach. With this study, we also wanted to discover whether it is appropriate to use this tool to explore the well-being of children and young people in the Czech environment of social services.

Experience from the research has shown that tools based on the Capability Approach were accepted without difficulty by children. Our young respondents actively participated in identifying capabilities that they considered important for their lives. The involvement of children in the research design was also facilitated by the fact that one of the important components of this approach is the emphasis on the individual experience; wishes and aspirations of the people interviewed. It is particularly the emphasis on these characteristics of life that became an important factor of their active participation in the research.

We believe that in using this tool, we have gained significant findings about the lives of these children and young people using social services. We consider the findings that point to the absence of hope in the lives of the children to be particularly serious. We believe that this requires special attention and for us to consider whether the childcare system itself does not create dispositions for the absence of hope for the future of children and young people. We believe that focusing primarily on material conditions may help children to live better in the present; however, this approach may not positively affect their future. For this reason, we believe that there is a need to make significant changes to the childcare system to ensure their well-being. One of the most important changes we see is that we should seriously consider how to invite children and young people to participate in creating their own concept of well-being. We should allow ways for them to participate with regard to their own development and source of freedom.

Although our research has not captured the reason why children in the care of social services do not look to their future with hope, other studies show that active participation of children in

determining their own life opens a space in which they learn to take responsibility for their lives and exploit potential of their creativity. These abilities are also important in the prevention of risky phenomena such as bullying, addiction and other pathological behavior in children (Giant, 2014; Navratilova, 2015). They are also the basis for children and young people to develop resilience for surviving in difficult life situations (Ruzickova & Punova, 2018).

Research on child well-being has brought many challenges to the conceptualization of social services. We believe that within these concepts, we should create a space for involving children and youth in determining the form of what is offered by these services. Although the services are conceived on the basis of community planning (which means there is an opportunity to involve the users of the services), it is still only adult-oriented perspective that is considered. Not only are children uninvolved in the process of negotiation about the form of these services, but this possibility is not even considered.

From the perspective of the content of the service offer, it is clear that certain services are absent; such services involving capabilities that would help children learn practical ways of how to live responsibly in society. Practical experience from the field shows that "overloading the client with services" leads to client dependence on services as well as a low level of responsibility for their lives. Within these services, children and young people should have the opportunity to engage responsibly in the resolution of their life situations.

Furthermore, the offer of social services pays very little attention to existentially sensitive topics such as child identity, their self-development and using their potential for their current and future functioning. The absence of these topics can also be a source of some uncertainties: low self-esteem and disorientation as to who they are and who they would like to be. This could also be a source of the low degree of hope for the future that the children/youth expressed in the survey.

Attention that is dedicated to children and young people who are being helped by professionals is mainly seen from the perspective of securing their rights and fulfilling their needs. Although respecting children's rights and providing for their needs play a key role in their protection,

we do not place enough emphasis on the aspect of prosperity which relates to the high quality living of one's own life. We believe that there is a need within the offer of services to steer slightly away from the perspective of securing children's rights and needs – towards one of supporting their reflective capabilities to handle life. Today's late-modern times require new types of skills: children and young people need to learn to cooperate with others; to negotiate and to have dialogues. They need to learn how – in an uncertain world – to build their own successful existence.

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# Clinical, Demographic and Psychological Predictors of Quality of Life in Patients with Osteoarthritis

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Original Article

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## Abstract:

**Background:** To select the appropriate strategies for treatment of osteoarthritis, it is advisable to assess not only the functional disorders but also their psychological and social aspects. The study objective was to examine the relationship between quality of life in patients with osteoarthritis and selected clinical, demographic and psychological factors. **Sample:** The sample consisted of 49 respondents with a medical diagnosis of osteoarthritis of the hip.

## Introduction

Osteoarthritis is a degenerative disease which affects a joint cartilage followed by a subchondral bone, joint capsule, synovial membrane, peri-articular muscles and tendon-to-bone insertions (Lukacova, Lukac, 2015). It is a common disease whose incidence has been increasing in both genders, particularly with age (McAlindon, *et al.*, 1999). The causes of the disease may vary. Osteoarthritis and its prevalence in people older than 65 years of age is described as the most frequently present gonarthrosis, then osteoarthritis of small joints in hands and coxarthrosis (Lukac, Lukacova, Rovensky, 2004).

The disease is manifested by pain, and functional disorder and thickening of a joint (Lukacova, Lukac, 2015). Physical disabilities and an inability to perform the activities of daily living occur in patients because of the disorders of the locomotor functions (gait, ascending or descending, stairs, sitting, and standing) (Rogind, *et al.* 1998).

In general, chronic pain and psychological disorders are present in patients with osteoarthritis (Goldenberg, 1989). Often, depression and anxiety worsen, particularly related to long-term pain (Lukac, Lukacova, Rovensky, 2004). In comparison with depression, anxiety is often an overlooked psychological comorbid symptom of osteoarthritis (Marks, 2015). Chronic pain increases comorbid anxiety and depression in patients with osteoarthritis (Hansen, Streltzer, 2005; He *et al.*, 2008).

Recent studies have shown that also anxiety levels and depression can alter threshold perceptions of pain (Hansen, Streltzer, 2005). Analysis of 13 studies which focused on the prevalence of anxiety and depression in patients with osteoarthritis found that their prevalence correlated with pain intensity, severity and location (Sharma *et al.*, 2016). The results of many studies suggest that patients with osteoarthritis accompanied by anxiety state more intensive pain, and less optimal outcomes in treatment are found in them (Marks, 2015). Attention has been paid to research and diagnosis of anxiety in patients with osteoarthritis because new information will contribute to favorable prospects in treatment and care for patients with osteoarthritis (Roy-Byrne *et al.*, 2008; Marks, 2015).

Treatment for osteoarthritis must be complex.

It requires patient's participation, and interdisciplinary cooperation between rheumatologists, orthopedists, psychiatrists, general practitioners and other specialists. The goal of treatment is to slow down the progression of the disease, relieve pain, suppress inflammation, and maintain and improve the quality of life. Physical therapy is an important part of treatment (Lukac, Lukacova, Rovensky, 2004).

Osteoarthritis affects human society as a whole. Besides pain and functional disorders, it causes other health problems. A more sedentary lifestyle contributes to an increase in occurrence of cardiovascular problems, osteoporosis, obesity, and psychological problems (Ozctin *et al.*, 2007). The disease is characteristic of an onset of other comorbid difficulties which restrict an ability to perform activities of daily living, and thus significantly reduce quality of life in patients (Montin *et al.*, 2007; Kawano *et al.*, 2015). An assessment of quality of life demonstrates an influence of chronic diseases on the patient's condition. To select the appropriate treatment strategies, it is necessary to assess not only functional disorders but also psychological and social aspects of these disorders (Ozctin *et al.*, 2007).

## Objective

The study objective was to examine the relationship between quality of life in patients with osteoarthritis and selected clinical (pain level, disease duration), demographic (gender, age) and psychological (anxiety) factors.

## Sample and methods

The research was conducted as a prospective cross-sectional descriptive study. A target group included the patients with the medical diagnosis osteoarthritis of hip (in accordance with the ICD-10, code M-16.0 – 16.9) hospitalized at the Orthopedic Clinic in Nitra. The sampling criteria included patients with an indicated surgical treatment and a respondent's informed consent with research. The sample consisted of 49 (100%) respondents, including 38.8% of men and 61.2% of women. The respondents' age ranged from 38 to 79 years ( $M_{\text{age}} = 59.24$ ;  $SD_{\text{age}} = 8.46$ ), with an average disease duration 3.12 years ( $SD = 2.9$ ).

The data were collected from October 2015 to February 2016. Measurements were conducted

by a nurse trained by a psychologist for administration of the used scales. The research was approved by the Hospital Ethics Committee.

The questionnaire SF 36 was used to measure quality of life, and was supplemented with demographic (gender, age) and clinical (disease duration) items. The HADS (Hospital Anxiety and Depression Scale) was used to measure anxiety and the Numeric Pain Rating Scale was used to measure pain levels.

The questionnaire SF 36 is generally sensitive to all physical health problems and also to general mental health. The questionnaire can be used to detect quality of life in a wide range of diseases, for example schizophrenia, breast cancer, depression, asthma, mood disorders and anxiety states, carpal tunnel syndrome, and many others (Ware, Sherbourne, 1992). The questionnaire consists of 36 items divided into eight dimensions: physical functioning; physical limitations; bodily pain; general health; vitality; social functioning; emotional issues; mental health. These dimensions are divided into two areas: 1) general physical health and 2) general mental health (Ware, Kosinski, 2001). The questionnaire contains one item which is not included in any of the areas. This item describes health in general compared to one year ago. In the questionnaire, the higher scores suggest a better HRQL (Health-Related Quality of Life) index. The score ranges from 0 to 100 points. The scores below 50 can be interpreted as below the norm of the general population. The lower SF 36 scores suggest, for example, worse health status (Ware, Sherbourne, 1993).

The HADS (Hospital Anxiety and Depression Scale) is a gold standard to measure anxiety and depression in patients (Zigmond, Snaith, 1983). It is a 14-item self-assessment scale which measures patient's mental status in a recent week. 7 items relate to anxiety and 7 relate to depression. In the study, we used a short version of the scale – the version HADS-A to measure anxiety. Each item is rated on a 4-point scale. A sum of each rated item is a total score. The scores 0 – 7 mean a status without anxiety, 8 – 10 a cut off for anxiety, and 11 – 21 severe anxiety (McDowell, 2006). The scale has good reliability (Cronbach  $\alpha = 0.75$ ) (Bjelland *et al.*, 2002; McDowell, 2006).

The Numeric Pain Rating Scale measures

pain intensity. The scale is one of the most commonly used scales to assess pain. The administration of the scale is not difficult. It is a segmented numeric scale with whole numbers 0 – 10, with 0 representing “no pain” and 10 representing “worst pain”. The scale has good reliability (Cronbach  $\alpha = 0.75 - 0.89$ ) (Farrar *et al.*, 2001; Rodriguez, 2001).

We used the software SPSS 22.0 for statistical analysis of the data. The arithmetic mean, standard deviation, frequencies and percentages were used as descriptive characteristics. To evaluate the results, we used a multiple linear regression analysis (the Enter method) which measures statistical significance of all predictors and a total amount of variance explaining a dependent variable (Tabachnick, Fidell 2007).

## Results

An average level of general physical health in the patients with osteoarthritis was 34.0 (SD = 14.8) and of general mental health 49.9 (SD = 19.2). An average pain level was 7.39 (SD = 1.2). The anxiety level was 9.08 (SD = 4.4) in average; 39% of the patients were without anxiety, increased anxiety was found in 16% of the patients, and severe anxiety was found in 45% of the patients.

We conducted the analysis in 2 models for a dependent variable: general physical health and general mental health.

**Table 1** General evaluation of prediction models of quality of life in patients with osteoarthritis

	R	Adj R <sup>2</sup>	F	p
Model 1 (DV: General physical health)	0.516	0.267	3.126	.017
Model 2 (DV: General mental health)	0.692	0.479	7.909	<.001

NB: Predictors: Gender, Age, Disease duration, Pain, Anxiety

The 1<sup>st</sup> model evaluates the predictors of general physical health. The model is statistically significant (F = 3.1; p = .017, Adj R<sup>2</sup> = 0.27), the variables explain almost 27% of variability of

**Table 2** Regression coefficients of predictors of 2 prediction models of quality of life in patients with osteoarthritis

		B	SE(B)	$\beta$	t	P
Model 1 (General physical health)	Gender	-3.243	4.099	-.107	-.791	.433
	Age	.126	.244	.072	.519	.606
	Disease duration	.183	.763	.036	.241	.811
	Pain	.659	1.606	.055	.410	.684
	<b>Anxiety</b>	<b>-1.674</b>	<b>.473</b>	<b>-.499</b>	<b>-3.541</b>	<b>.001</b>
Model 2 (General mental health)	Gender	-.335	4.461	-.009	-.075	.941
	Age	.090	.265	.040	.340	.736
	Disease duration	.297	.830	.045	.358	.722
	Pain	-.400	1.748	-.026	-.229	.820
	<b>Anxiety</b>	<b>-3.066</b>	<b>.514</b>	<b>-.707</b>	<b>-5.960</b>	<b>&lt;.001</b>

NB: B – unstandardized regression coefficient, SE(B) – standard error of unstandardized regression coefficient,  $\beta$  – standardized regression coefficient, t – t-test, p – statistical significance

general physical health in the patients with osteoarthritis (Table 1). Out of all studied variables (gender, age, disease duration, pain, anxiety), only one variable – anxiety – explains general physical health ( $\beta = -.499$ ;  $p = .001$ ) (Table 2).

The 2<sup>nd</sup> model evaluates the predictors of general mental health of the same variables. The model is statistically significant ( $F = 7.9$ ;  $p < .001$ ,  $\text{Adj } R^2 = 0.48$ ), the variables explain almost 48% of variability of general mental health (Table 1). The only significant predictor, as in the first model, is anxiety ( $\beta = -.707$ ;  $p = .001$ ) (Table 2).

## Discussion

In the study, we measured quality of life in the patients with osteoarthritis. An assessment of quality of life is an inherent part of the process of care and treatment in patients with osteoarthritis (Lukac, Lukacova, Rovensky, 2004; Jakobsson, Hallberg, 2002), because it demonstrates an influence of functional disorders on all aspects of patient's life. Jakobsson & Hallberg (2002) analyzed 17 studies which measured quality of life in patients with osteoarthritis. In the analyzes, they found that none of the studies had included respondents older than 75 years of age, which

they considered a serious limitation, because it is important to address the age group of patients older than 75 years, too. In our study, we also reflected on the request; the respondents' age ranged from 38 to 79 years ( $M_{\text{age}} = 59.24$ ;  $SD_{\text{age}} = 8.46$ ).

In the study, we found that the average level of general physical health in the patients with osteoarthritis was below 50, i.e. below the norm of the general population. The lower score of SF 36 suggests worse health status. Shalaby & El-Sayed (2017) assessed quality of life in patients with gonarthrosis with the use of the questionnaire SF 36 and found scores lower than 50 in all domains except the domain mental health. Similar findings are stated by Ferreira *et al.* (2015); in the study on quality of life in female patients with gonarthrosis they found lower quality of life in comparison with the general population.

Several authors focus on research in the area of measurement of quality of life in patients with osteoarthritis, particularly related to: pain (Jakobsson, Hallberg, 2002; Creamer, Lethbridge-Cejku, Hochberg, 1999), demographic factors (Creamer, Lethbridge-Cejku, Hochberg, 1999), and depression and anxiety (Blixen, Kippes, 1999; Creamer, Lethbridge-Cejku, Hochberg,

1999; Ozcetin *et al.*, 2007; Montin *et al.*, 2007; Marks, 2015; Ferreira *et al.*, 2015; Shalaby, El-Sayed, 2017).

In the research, we focused on studying the relationship between quality of life in patients with osteoarthritis and pain level, disease duration, gender, age, and anxiety level. We found that pain level was much closer to the value “worst (unbearable) pain”. The average anxiety level meant a cut off of anxiety, and similar findings on anxiety level in this group of patients are confirmed by other authors, too (Montin *et al.*, 2007; Shalaby, El-Sayed, 2017). In our sample, anxiety was present in 61% of respondents; the studies state anxiety in 50% of patients with osteoarthritis (Marks, 2011; Gandhi *et al.*, 2015).

The studied clinical (pain level, disease duration), demographic (gender, age), and psychological (anxiety) factors explained the statistically significant relationships in both areas of quality of life (general physical health and general mental health), more in the area of general mental health. Jakobsson & Hallberg (2002) found that pain, functional limitation and higher age decrease quality of life in patients, and thus they support our findings.

We found that, out of the 5 studied variables, independently only anxiety levels predict general physical and mental health. The worse anxiety the patients experienced, the worse assessment of their physical and mental areas of quality of life. Experiencing anxiety is more manifested in the area of a psychological aspect of quality of life; however, even an influence of anxiety on a physical aspect of quality of life is not negligible. Also, according to Ozcetin *et al.* (2007), there is a strong negative correlation between anxiety and quality of life in patients with osteoarthritis. Marks (2015) states that anxiety and depression negatively influence quality of life in patients with osteoarthritis. Lunghi, Miller & McQuillan (1978) state that patients with osteoarthritis with higher anxiety levels had worse health status. Axford *et al.* (2010) state that anxiety levels in patients with osteoarthritis correlated with functional disability level.

According to our findings and findings by other studies, we can consider anxiety to be a significant predictor of quality of life in patients with osteoarthritis. Anxiety accompanying a dis-

ease influences physical, functional and social well-being and health status of patients (Castano *et al.*, 2015). It is a predictor which is to be taken into account in treatment and care in order to achieve optimal outcomes in the patient. Marks (2015) states that patients with osteoarthritis with anxiety experienced more pain, visited hospital more often, used more drugs, and their recuperation took longer. In the present, the treatment of osteoarthritis has a lower tendency to focus on anxiety reduction despite the fact that anxiety is detected in up to 50% of patients (Marks, 2013; Gandhi *et al.*, 2015). Several studies confirm the need to assess patients' mental status in order to optimize functional outcomes in patients with osteoarthritis (Tallon, Chard, Dieppe, 2000).

## Conclusions

To select the appropriate treatment and care strategies for patients with osteoarthritis, it is necessary to assess their quality of life (Ozcetin *et al.*, 2007), because it is a disease which is typical of an onset of comorbid difficulties which restrict an ability to perform the activities of daily living, and thus influence various aspects of patients' life. Also, many studies state it is necessary to assess anxiety levels in order to optimize functional outcomes in patients with osteoarthritis (Tallon, Chard, Dieppe, 2000). The findings in our study also suggest that anxiety accompanying the disease influences both physical and mental status in patients (Castano *et al.*, 2015). Particularly, the multidisciplinary approach and psychological support are recommended in care for patients with osteoarthritis.

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# Barriers in Education of Children from Socially Disadvantaged Environment

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Original Article

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## Abstract:

The paper discusses and summarizes the knowledge in the field of education of socially disadvantaged children with an emphasis on the Roma ethnic group in Slovakia. It focuses on the issue of pre-primary education of these children and points to the specifics that have a negative impact on the adaptation to the school educational process. The paper addresses the risk aspects of poverty, social exclusion, child development and the need for early intervention for families with children. Furthermore, in the article we focus on the support of children at the community level and on possible forms of aid that can help to achieve a more favorable development of the overall Roma family within specific projects. We also deal with early care, which is very important for the bio-psycho-social development of children and youth.

In the animal kingdom, a human being, as a biological entity, is a certain anomaly, an oddity. Not only because of the ability to think and speak abstractly, but also because it is born to the world as a biologically and mentally 'incomplete' being. It lives through its youngest years in a 'social incubator', in which with the help of other people, it gradually learns to overcome the thread to its natural and spiritual existence. Human company is the natural environment for every human individual, thanks to which it becomes a fully-fledged personality. Thus the company to which human offspring, a child, is born is a non-negligible fact.

Nowadays, the thesis stating that a human is a being formed by natural forces (heritability, innate talents, nutrition, natural environment, ...); social factors (family, school, broader social environment, culture, ...); upbringing (intentionally organized activity) is universally accepted. It follows that the character of the 'social incubator' in which a child lives and grows up which is usually a family and the closest company of people, significantly influences what a person as an individual will be like in relation to himself, others and the surrounding world.

Thus after birth every person is growing into a particular cultural environment which mediates certain characteristic attitudes, opinions, experiences and knowledge to her/him. Every society then creates its institutions to it, from those family and school play an irreplaceable role in our culture. They are transmitters of cultural content, moral order and system of values, which are necessary for the child to be able to fully participate in society and cultural conditions created by it in the future.

Law No. 245/2008 on raising and education of children (school law) and about changes and additions to some laws, § 2, article p): "child from socially disadvantaged environment or student from socially disadvantaged environment [is considered] a child or a student living in an environment which according to social, familial, economical and cultural conditions insufficiently stimulates a child's or student's mental, voluntary, emotional qualities, does not support its socialization and does not provide a sufficient amount of impulses for personal development. It is about defining a child according to the characteristics of environment the child lives in."

With 19 million children living below the poverty line in the EU-27, lowering child poverty and supporting social integration is a key political sphere of the European Union. In political documents of the EU, the importance of measures specifically focused on the most disadvantaged regions and those the most threatened by poverty, as incomplete families, minorities and disabled people, are becoming more and more acknowledged. The Roma population is one of the biggest and the most socially disadvantaged ethnic minorities in the EU. There are 10 to 12 million Roma people scattered through the European continent concentrated mainly around central and eastern Europe. It concerns a relatively young population; in certain countries there is 50% of the Roma citizens that are younger than 18 years. But most of the Roma children live on the periphery of society, in poverty and excluded and their situation has been significantly worsened in many countries throughout the last two decades.

"In Slovakia, the Roma population is one of the most vulnerable social groups threatened by poverty and social exclusion. These groups are commonly referred to as marginalized Roma communities. Out of total 450,000 Roma people living in Slovakia, 250,000 to 260,000 of them is socially endangered (marginalized). The highest concentration of socially excluded communities is recorded in eastern Slovakia and southern regions of central Slovakia. This part of the population is exposed to extreme poverty which is spread to other generations. 29% of registered settlements do not have electricity; 81% of them do not have sewerage system; gas is not present in 59% of the settlements; water pipeline is absent in 37% of the settlements; 20% of the settlements does not have blacktop driveway. Out of all the settlements; 149 of them are considered segregated which means that the settlements are located on the periphery or out of a municipality or town. Nearly  $\frac{1}{3}$  of the settlements in Roma settlement villages are illegal (primarily shacks, portakabins, non-residential buildings, but also houses). The highest ratio of illegal settlements (49%) are settlements out of a municipality/town. The most common type of illegal settlement are shanties. They add up to 16% of all settlements and 14% of inhabitants of Roma settlements live in that type of settlement. The highest ratio of shanty inhabitants are also in the settlements out

of a municipality/town. Inhabitants of the shanty settlements add up to 21% of the total number of inhabitants living in this kind of settlement.” (Slosar, 2009, s.492)

A big part of Roma population suffers from marginalization, poverty, exclusion and general refusal by the majority population. Throughout the last 2 decades their situation has significantly worsened in many countries. The environment for Roma children is characterized by isolation, poverty and exclusion. Bad housing conditions and bad infrastructure are even worsened by the regression of residential countries. Inhabitants of neglected quarters suffer from legal insecurity and often lack ownership rights, so their homes are not official and because of that they cannot register at their residence address. Due to this situation, basic services are inaccessible for them; practically “invisible”, they live on the periphery of society where no one cares about them.

Education, of which level is influenced by residential segregation, aside from other thing, too, is very insufficient and limits access of Roma people to the labor market, and that leads to poverty and exclusion which most of the Roma people encounter nowadays. A lot of Roma people do not complete elementary education; only few of them finishes high school and a small minority obtains a university diploma.

While investigating the issue of early education of children from the marginalized Roma community, we have to become aware of two different approaches. On one hand, we speak about a different value system and cultural difference of Roma people which lead to the incapability of children to adapt to education system, and on the other hand, we mention social aspects of poverty to education which influence the failures of Roma people from marginalized communities.

An author mentioned below states that in the present day “it is not possible to definitely determine, which of the behavioral patterns in the community are the result of traditional lifestyle and which are the feature of poverty culture.” (Necas, Ondrej Hala, 2010, s.493)

If we mention a different value system, it is manifested in different upbringing of children than the upbringing of the majority population. Prejudices like ‘Roma people do not take care of their children’ are not true. They take care of them, but differently. And the social difference is

incompatible with the majority population. Roma people from socially disadvantaged environments are stimulated differently from an early childhood as a result of the neglected environment. That is why their intellect develops more slowly. Even though intellect itself does not determine success in school, it is important for persistence, diligence, emotional and social stability. Existence of segregated Roma schools is a sign of a more general problem, the existence of Roma ‘ghettos’. Desegregation thus represents a problem not only for the school, but for the whole society. In many cases, the only kind of solution of the education situation is to firstly solve the situation in the Roma settlement villages. Desegregation, however, does not mean simply placing Roma and non-Roma children to one class. To break the vicious circle of exclusion it asks for an integrated long-term approach focused on making the people living in disadvantaged regions economically independent and increasing the quality of services. Unfortunately, many governments continually fail to adopt necessary measures.

Children have a basic right for equal, accessible help in developing their abilities and skills and for upbringing in family, regardless of region of a country or size of a settlement village. Child-care system’s responsibility is to organize its services in a way it is equally accessible to all children, suitably to their age and needs. In many cases, development deficits of children are not discovered until beginning of school. This is huge disadvantage for children with special educational needs and their families.

When mentioning excluded settlements where people living in generational poverty are all concentrated in one place, we have particularly Roma inhabitants in mind. They fell to the deep poverty gap immediately by being born into the environment a fall deeper to the gap everyday. Without assistance of helping professions, they would have hardly make it out. Individuals and experts who help them in various problems, simultaneously become ‘members’ of their families, their lives. They gained trust with the empathetic attitude and build a bridge towards help and support with it.

At the beginning of the work, it is difficult to decide what to begin dealing with first, housing, employment rate, accessibility of drinking water,

education, low financial literacy, health or unsuitable living conditions. Problems, mentioned above which they have to face every day and are the cause of exclusion, are present in every excluded community.

### **Need for Early Care for Children in Roma Families**

The Roma community is specific in its own way and distinctive from the majority population. As was already mentioned, a fundamental pillar in upbringing of a Roma child and at the same time a central pillar in formation of child's personality is family. (Horňák, 2001) Socialization in Roma family:

- “upbringing is not individualistic, but collectivistic, it does not aim for bringing up an individual, but a member of wider family,
- everything is dealt with collectively, individual decisions are not recommended,
- 1st rule in a child's upbringing is its freedom,
- it is not expected of the child to make any effort while fulfilling school assignments,
- parents with the lowest education do not feel the need to change the way of living (instinctually, they see it as a problem of majority population) and they give their children just the same mindset,
- family protects the child, it is its sanctuary, but at the same time a border which cannot be overstepped,
- family hands the child in its Roma values, traditions, culture, philosophy of thinking and living, and that includes the rejection of way of thinking and living of the majority population.” (Matulay, 1999, s.45)

When talking about a different value system, this is expressed mainly in a different way of bringing up children in comparison with the way of bringing up children in majority population. Director of Center of Research of Ethnicity and Culture, E. Kriglerová points out that traditional Roma family equals community upbringing. Within the community, socialization takes place through widespread family connections. That gives children a strong emotional base. Roma children are independent from an early age; they are brought up to be so. They learn communication, verbal and non-verbal, from adults. Children watch and observe them, listen to them, and learn values through that. She states, that children are

brought up as little adults. (<https://osf.sk/pribehy/pribehy-eea/romske-deti-vdetskych-domovoch-tvoriva-vacsinu-chybaju-podmienky-na-ich-adaptaciu/>).

While looking at old Roma family photos, we see mothers carrying their children tied to their bodies by scarfs in many pictures. It is obvious they were very close. Mothers were always prepared to feed and change their child. In the early phase of upbringing parents thought it is enough to satisfy the needs of children immediately.

Children develop in many ways and learn at a different rate, too.

M. Bartonova (2005) agrees that the environment in which a Roma child grows up is different in culture, language and set of values. In contrast with a majority children who grow up predominantly in nuclear families, Roma children grow up in a family with many relatives. Bartonova presents emotionality as an important fact. Children are often not given stimuli through books and painting tools. It results in insufficiently developing fine motor activity. Because they mostly think only about the present, motivation is another problem on the path to education. Other setbacks are the inability to concentrate and insufficient persistence.

As I. Radicova (2001) states, the approach of Roma people to education strongly depends on the type of family they come from. Parents from a marginalized Roma community and their children view education as an obligation towards the state, not their children. In settlements, where Roma people are integrated and are included in broader social network, their basic needs are satisfied and differentiated perception of poverty, education itself gains in value.

We cannot omit the fact that every child who comes from stimuli-deficient environments needs a specific, individual approach from teachers, tutors and other professionals. New trends, approaches and methods of education based on the principle of humanism and understanding of cultural, ethnical, social and educational specifics have to be used. Only if all the principles are followed, signs of trust from the members of the Roma community can be expected. This will be expressed in the effort and willingness to participate, and thus fulfill mutual societal goals; increasing the quality of pre-elementary and elementary education of Roma children. Actually

we have to be aware that without proper cooperation of Roma people, all the effort would be useless, and by that the misunderstanding between the minority and majority population would be deepened.

Nowadays, the environment of segregated localities and generationally reproduced poverty is a precondition of negative development of early childcare. It is important to deal with the socio-economical situation of a community as a whole; but it is also important to focus on prevention, education and support for families with children.

In many cases, we can talk about parental failure, their insufficient EQ or emotional perception of the child's situation, lack of interest or pathological negligence of the child. But we can equally proceed from total poverty of parents, influence of socio-pathological behavior, psychological or mental characteristics of individuals. Social control and surveillance, activation of family and community, and mobilization of socio-legal protection of the child and organs focused on its protection are part of the protective factors in the situation. When an appropriate combination of intervention for the wellbeing of the child, internal and external motivation, support service and individualistic approach is used, it is possible to overcome the deficiencies and risks on the parental side even though it is hard target.

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# Migration as Pursuit of the Social Determinants of Health

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## Abstract:

Immigrants, refugees and displaced persons are often a source of political and diplomatic tensions as they move away from their homelands. Their movement is often viewed with hostility by those they encounter in their travels. But most of these travelers are merely seeking a better life as evidenced by pursuit of social determinants of health. Their right to this pursuit is reflected in international law and by recognition of principles of social justice.

## Introduction

In recent years, approximately 60 million individuals have been classified as immigrants, refugees or displaced persons at a given time. Whether these people are moving across international borders or within their own homeland, some are moving of their own volition while oth-

ers feel compelled to move because of conditions in their home locales.

Those who immigrate are not always made to feel welcome on their journey. Whether they move within their own nations as displaced persons or cross international borders in pursuit of better lives as immigrants or refugees, they often

face forceful opposition from the native populations they encounter. Political opposition often confronts those seeking asylum and temporary or permanent residence in a new nation or locale within their home nations. They are often viewed as invaders by those whose territories they move through or to.

A closer examination reveals that immigrants are not seeking to do harm to those they encounter. Rather they tend to seek improvement in their lives by pursuing social determinants of health often denied to them in their homelands. Their right to pursue these social determinants is supported in international law and reflected in the principle of social justice.

### **The Migratory Process**

People have moved about on the earth since the earliest of times. Marceca (2017) believes the migratory phenomena referred to as „Out of Africa II“ started in North-Eastern Africa 70,000 years ago. Shah (2020) writes of pre-historic migration from Asia to an expanse of the Pacific Islands beginning approximately 5,000 years ago. Between the years 1880 and 1930 she writes that more than 27,000,000 people entered the US (ibid).

In general, migration occurs because people seek a better life, believing that their destination will represent an improvement over the place from which they came. Rosen & Young (2016) distinguish between migrants and refugees or asylum seekers. Although both participate in the migratory process, they define refugees as those „who are fleeing armed conflict or persecution, and who would be in danger if forced to return to their own countries.“ Migrants are usually seeking to improve their lives by finding work, pursuing education, or reuniting with family members. They are generally free to return to their home countries if they so desire.

According to Marceca (2017) „the migratory phenomenon have been widely examined from historical, social, economic, and cultural perspectives, (but) health and health care perspectives are understudied.“ He writes further of the need to analyze the health needs of migratory populations, the education and training of health social workers providing care to migrants and the necessity of evaluating „health outcomes of the migrant population and the impact of adopted health policies“ (ibid).

The World Health Organization (2019) published a draft global action plan entitled „Promoting the health of refugees and migrants.“ Among its pronouncements is the following:

Although their treatment is governed by separate legal frameworks, refugees and migrants are entitled to the same universal human rights and fundamental freedoms as other people. Refugees and migrants also face many common challenges and share similar vulnerabilities. The Secretariat will focus on achieving universal health coverage and the highest attainable standard of health, as mandated in WHO’s Constitution, for refugees, migrants and host populations within the context of WHO’s Thirteenth General Program of Work, 2019-2023) (ibid)

Although the WHO’s pronouncements are laudable, Gostin (2019) writes that its achievements in the field of immigrant health have been less stellar. He writes:

To achieve its goals, WHO will have to persuade governments to treat migrants humanely, while affording them equal health and social benefits. But in a world of rising nationalistic populism, that is a hard sell. Governments view asylum-seekers as culturally and religiously incompatible with their country’s cultural values, or as a financial burden they don’t want (ibid).

Immigrant populations may be expected to encounter health problems related to their locations away from home. More than three million displaced Syrians living in crowded camps and informal settlements in northwestern Idlib province might have been exposed to COVID-19 when a hospital physician was diagnosed after having contact with up to 300 patients (Coles & Osseiran). The lack of PPE at the hospital combined with poor sanitation in the camp and settlements increased the fear of spreading infection (ibid).

A refugee camp named *Moria*, on the Greek Island of Lesbos, further illustrates the COVID-19 related health risks forced by refugees. Migrants from Syria, Afghanistan, Iraq and other countries inhabited a camp of tents, housing containers and ramshackle self-made shacks squeezed together in close proximity (Abdulahin, 2020). A 17-year old asylum seeker living in the camp said:

With the coronavirus you have to avoid going to crowded places, keep yourself clean, don’t go outside. In Moria camps you have to go outside.

For toilet, for shower, for food. And every time you go outside you are in a really, really big crowd of people (ibid)

In addition to health problems that migrants may encounter in holding areas or sometimes at their destinations, their journey may also be problematic. While in transit, they may also be exposed to unsanitary conditions that may facilitate the spread of disease and treatment capabilities may be severely limited for numerous reasons.

However, the migrants' point of origin may also prove detrimental to their health. The World Health Organization (2012) defined social determinants of health as „the conditions in which people are born, grow, live, work and age. These circumstances are shaped by the distribution of money, power and resources at global, national and local levels“ (ibid).

Among the specifically identified factors are:

- Income and social status
  - Education
  - Physical environment
  - Social support networks
  - Genetics
  - Health services
  - Gender
- (WHO, 2017)

The „northern triangle“ of Central America represents an interesting geographical region for the study of immigration. Comprised of El Salvador, Honduras and Guatemala, the region has long comprised of both a route of immigration to the USA as well as a source of an immigrant population. Shah (2020) writes that European and African immigrants have long traveled to South America and then made their way north through Central America in transit to Mexico and the United States. In more recent times, a larger segment of the „iron triangle“ population has become part of the migratory push northward, to include unaccompanied minor children sent by their parents.

The humanitarian crisis in Syria is a glaring example of the plight of refugees and displaced persons. According to the Brookings Institution (2018) over half the Syrian population has been forcibly displaced. A little less than one quarter of the world's population of 25 million refugees are from Syria and residing in Jordan, Lebanon and Turkey. Syrians also account for 6 million of the world's 40 million internally displaced per-

sons, still remaining within the nation's borders.

Syrian refugees and internally displaced persons are victims of Syria's long simmering civil war. Central American refugees have made their way to the USA, primarily because of living conditions in their home countries which equate to the common understanding of the social determinants of health.

The Immigration Forum (2019) claims that the most recent research findings indicate that immigrants strive to come to the US because of „push factors“ that cause them to leave their countries of origin“... primarily because of real fears about their futures“ (ibid). These include: „violence, gender inequality, political corruption, environmental degradation and climate change, as well as lack of access to adequate health care and education“ (ibid).

Zoe Carpenter (2021) writes:

What is happening now is not so different from previous spikes in the number of children crossing the border in 2014 during Barack Obama's Presidency, and in 2019, under Donald Trump. Then as now, many are fleeing violence and poverty ... In Guatemala the situation for children is increasingly dire because of last year's hurricanes, the economic impact of COVID-19 and crop failures linked to drought, all of which has contributed to food insecurity.

(The Nation, April 22, 2021).

### **International Legal Recognition**

Access to social determinants of health is an evolutionary concept reflected in international and public health law. An examination of the causes of migration reveals that immigrants and displaced persons are often forced to move to new locations as part of their efforts to access social determinants of health.

Lawrence Gostin (2014) writes that he views much of international health law as an extension of human rights law:

„...global health law encompasses the concept of health as a fundamental human entitlement, as well as encompassing multiple legal regimes outside the health sector. The right to the highest attainable standard of physical and mental health embedded within a large network of human rights, norms, institutions, and processes is a growing and expansive field that intersects with health

*The International Covenant on Economic, Social and Cultural Rights 1966* became effective 10 years later on January 3, 1976. As of October, 2010, 160 states had ratified the covenant. Among the rights specified in the covenant is „right to highest attainable standard of physical and mental health“ (Article 12)

Dixon *et al.* (2011) write of the obligation „a State owes to another State with regard to the treatment of that other State’s nationals within the first state’s territory.“ The authors indicate that a „denial of justice“ may result in „an action on the international plane.“ (p. 439).

At the southern US border with Mexico, unaccompanied children have presented themselves for asylum in the US. *The United Nations’ Convention on the Rights of the Child* (1989) stipulates that „states parties shall strive to ensure that no child is deprived of his or her right of access to....health care services.“ (Mark, ed, p. 82)

More specifically, the social determinants of health have been drawing increased scrutiny as evidenced by the adoption of General Covenant No 14 by the United Nation’s Committee on Economic, Social and Cultural Rights (Marks, p. 82). The comment was in response to the above-mentioned Article 12 of the International Covenant concerning the *Right to the Highest Attainable Standard of Health*. The comment reads in part:

The Committee interprets the right to health, as defined by Article 12, as an inclusive right extending not only to timely and appropriate health care but also to the underlying determinants of health, such as access to safe and potable water and adequate sanitation, an adequate supply of safe food, nutrition and housing, healthy occupational and environmental conditions, and access to health-related education and information... (ibid p. 84)

## Conclusion

Support for immigrant, refugee and displaced person’s pursuit of the social determinants of health can be found in international law. Although international law may sometimes be imprecise and subject to national law restrictions, it does provide authoritative and moral guidance on the migratory process. While a right to receive health care services has been long recognized for the migrant population, it would appear that the pursuit of the social determinants is now recognized as well.

Future research should focus on specific migratory experiences, the access to health care provided to migrant populations and realization of the social determinants by migrants. Increased emphasis should be placed on efforts to expand national legal protections for migrants.

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# Psychosocial Aspects and Quality of Life in Cancer Patients undergoing Surgery

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## Abstract:

**Introduction:** Quality of life in cancer patients and probably also long term survival is negatively affected with fear of the recurrence of cancer and consequences of aggressive therapy. This is the reason for anxiety, depressions, and frustration which are accompanied by cognitive, emotional and behavioral disorders in their physical, relationship, sexual and social functioning. The aim of our study is to analyze the dynamics of evolution of the psychosocial loads and qualitative changes its symptomatology in cancer patients who survival 1-4 years after surgery.

**Material and methods:** For assessment of psychosocial morbidity's in measure in surgery patients standardized questionnaires of European Organization for Research and Treatment of Cancer- questionnaire EORTC QLQ-C30.3 (Quality of Life-C.30.3) and its module EORTC QLQ- BR23 were used.

**Results:** The degree of psychosocial mortality in survival patients one year after MRM in our group clearly demonstrated that these patients suffered because of consequences of psychosocial loads. It results from fear of recurrence of cancer and next functional, emotional, cognitive and social disorders without regard for surgery range. The degree of psychosocial loads in patients after MRM is still more than 4 years after end of treatment. Results show, that after the end of treatment there are many changes in their lives - anxiety and depressions can lead to psychical lability because of higher doubts, nervousness, irritability, helplessness and loneliness in their sufferers.

**Conclusion:** Out-patient psychosocial interventions and preventions because of negative impact of ongoing and changing psychosocial loads becomes necessary. It means that there is negative impact on quality of life; of long term cancer remission and survival of patients after surgery.

## Introduction

Breast carcinoma (BC) is the most frequent oncological disease in Slovak women and its incidence is still rising. Mortality for breast malignity decreased about 8% in Slovakia between 2011 and 2016. Although in this period, the incidence of these diseases increased about 23%. Thanks to better screening it identifies more diseases in early stages (more than 75% of breast cancer is diagnosed in stages I and II) and the time of survival is longer. It is clear that the number of women with breast cancer with long term survival is increased (1).

Despite the increased trend of malignant disease's incidence in many European countries, mortality has decreased and has increased the number of patients who survival more than 5 years. Breast carcinoma is the most frequent carcinoma in women and the second most frequent disease (after colon cancer) in the population. According of WHO, in the last two decades in Europe there is a decrease in mortality because of breast carcinoma. Significant progress in this aspect is thanks to better screening of early stages of carcinoma. We use ultrasonography and mammography in routine clinical practice; better methodology; better strategy of treatment (2).

In Europe, recent meta-analyzes of breast carcinomas shows a 5 year period of survival in

treated patients reached 65-82% depending on the range and aggressiveness of a cancer. From all types of cancers 5 year survival in breast cancer patients is 23% world-wide (3, 4). This means there are 9.5 million women who must counter diagnosis of breast cancer and have to learn to live with this disease. They have to live with this progressive disease also in a no relapse period after undergoing difficult and mutilating curative treatment (5). In Slovakia, the number of survival patients increase about 1,200 every year by more than 2,000 new diagnostic breast carcinomas (2,198 cases in 2016-17. 7%). So finally, in a 5 year period there are 6,000 survival patients who have to fight with the consequences from diagnosis and treatment (1).

In a no relapse period, patients have to deal with consequences of aggressive, radical surgery (pain, asymmetry of breasts, shoulder fibrosis, edema of upper extremities) and subsequent adjuvant cyto-destructive therapy (fatigue, insomnia, weakness). In addition, psychosocial loads potentiate fear for recurrence of cancer disease; loss of femininity; feelings of powerlessness; loneliness; changes in sexual sphere; decrease of physician, family and social functionality. Despite this, there is a group of patients who are balanced with disease and positive fight against it. There is a group of patients with severe psy-

chosocial loads which means that their behavioral risk profile decreases total quality of life and which is leading into social isolation; apathy; loss of life interest and its filling. Previous analyses of psychosocial morbidity are basically focused on two fundamental parameters: anxio-depressive condition resulting from diagnosis and treatment of cancer; and second are manifestations of functional decrease in the cognitive-behavioral sphere. The aim of our study is to analyze the degree and dynamic of evolution of psychosocial morbidity and its consequences on quality of life in cancer patients who underwent radical mastectomy (MRM) with subsequent adjuvant radiotherapy 1-4 years after surgery with standardized questionnaire research (1).

## Material and methods

In the study were included and evaluated 105 patients (T2b–T3) with breast carcinoma who survival in a 1-4 year no-relapse period after MRM (average year  $60.5 \pm 14.0$ ). A distribution according of marital status was: single (6%); married or in partnership (61%); divorced (24%); widowed (9%). 95% women mentioned religion affiliation. Distributions in working condition were: employed (27%); self-contained (14%); unemployed (2%); housewife (33%); unformed job (2%); retiree (22%). Treatment of the disease was: surgery (96%); radiotherapy (35%); chemotherapy (77%); hormonal treatment (41%). Range evaluation of psychosocial loads and quality of life of 1-4 years survival patients (1 year  $\pm 3.7$  months) and 4 years ( $\pm 4.2$  months) after the end of treatment was analyzed using by standardized certificated questionnaires.

## Multidimensional questionnaires

In this study we used standardized questionnaires of the European Organization for Research and Treatment of Cancer - questionnaire (EORTC). They were an official Slovak version. 115 patients answered questions in the questionnaire during regular control examination in the Breast Surgery Outpatient Department.

## EORTC QLQ- C30 with module QLQ- BR23 – European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-Breast cancer Module

Questionnaire EORTC QLQ- C30 with module for women with breast carcinoma are questionnaires used for clinical research (2, 3).

EORTC QLQ-C30.3 questionnaire (6) includes questions about 5 functional scales which evaluate physical; family, emotional; cognitive; and social functions; 3 functional scale about clinical symptomatology and separate 7 items scale evaluate total quality of life of oncology patients.

QLQ- BR23 contains 23 items and is for patients after mastectomy and for every method of treatment. Questionnaire EORTC QLQ-B23 is module of previous questionnaire and it is for evaluate of treatment's side effects and next emotional dysfunctions. Both questionnaires are based on a scoring system of actual feelings of psychosocial deterioration. It used 4 items Likert's scale (absolutely no; a little; enough; very). Calculation of gross score of linear transformation into the scale of 1-100 and statistical evaluation were done according EORTC QLQ-C30.3 manual. Validity of results was statistical verified.

A questionnaire creates functional scale: physical self-image; sexual function; satisfaction with sexual life; fear of future health; and four symptomatic scale side effect of treatment; symptoms connected with arm of operating side; symptoms connected with treated breast; symptoms connected with loss of hair. Items (for example: Did your arm hurt?) are evaluated on a 4 points scale from 1 (absolutely no) to 4 (very). Answers responded to status during the last 7 days and last 4 weeks in the case of evaluating sexual life. Functional scales evaluate: zone of physical function; do the routine work; emotional zone; cognitive; social zone. In emotional scales are evaluated: fatigue; dizziness; pain; individual items evaluate: dyspnea; insomnia, loss of taste; obstipation; diarrhea; financial problems because of treatment. Items (for example:., Were you tired? ) are evaluated on a 4 points scale from 1 (absolutely no) to 4 (very). Items, which are connected with HRQOL (for example: How do you rate your health during last week?) are evaluated on a 7 points scale from 1 (very bad) to 7 (excellent) (6).

### **Questionnaire SLDS- BC - Satisfaction with Life Domains Scale for BC**

SLDS- BC is a 32 items self-assessment questionnaire which evaluates HRQOL in different phases of disease, from determination of diagnosis, treatment, until recovery. Items are evaluated on a 7 points scale. Patients choose pictures of faces (emoticons) from happy (1) to incredibly sad (7). There are 5 zones evaluated:

1. social functions (employments, relationships, overall satisfaction)
2. appearance (look, weight, life energy)
3. physical function (physical ability, healthy complication of disease and pain)
4. communication with medical stuff (physicians, nurses, other medical stuff)
5. spirituality zone (important and benefit of individual spirituality in treatment) (5).

### **Questionnaires applicable for physical self-imagining BIBCQ - Body Image after BC**

BIBCQ is a 53 items questionnaire about long-term influence of breast carcinoma treatment on physical self-imagining of women. It includes 6 optional items for women with both breasts and 2 optional items for women after one or both breast mastectomy. Items create 6 scales:

1. vulnerability (sensitivity of disease, for example: I'm afraid about my body?)
2. physical stigma (need to hide own body, for example: I cannot look at my body, on my scars after surgery...)
3. restrictions (feelings of physical ability, for example: I feel tired during the day.)
4. rating of body (satisfaction with body and look, for example: I am fine with my body.)
5. visibility (doubts about physical changes, for example: I feel, that they are looking on my chest....)
6. evaluation of upper extremities on the operated side (symptoms of hand and its look, for example: I have pain of my hand.)

Items are evaluated on a 5 points scale from 1 "absolutely no" to 5 "absolute agreement", or from 1 "never / almost never" to 5 "always/ almost always". This questionnaire is useful and undemanding (5).

### **MAS - Mastectomy Attitude Scale**

Questionnaire MAS has 33 items, and it is done within clinical study. It is oriented on

women's position after mastectomy. It reviews 7 zones: negative feelings about mastectomy; sexual sphere; satisfaction with look; life style; hiding of operated breast; honesty to theme of mastectomy; sense of importance of mastectomy. Individual items are evaluated on a 4 points scale from 1 "don't agree" to 4 "agree" (5).

## **Results**

### **Quality of life in survival patients with breast carcinoma**

For comparison of overall quality of life in patients with BC, who survival 1 and 4 years after MRM a 7-point scale (very bad to very well) is used. This data show that quality of life in the fourth year after MRM is not changed in all against first years survivals. These patients evaluate their quality of life as bad till tolerable (score 1-5, average 3.7 vs 3.5). In all groups there is no patient after MRM who evaluate her quality of life as very well (score 7).

### **Psychosocial determinates of life quality in survival patients with breast carcinoma**

Comparison of patient's psychosocial loads one year after MRM according to emotional parameters responded to low score of life quality. Parameters of sexual function; feelings of femininity loss; afraid of job; feelings of uncertainty; loneliness; afraid of future were very intensive after MRM. There are other items which are scored in patients after MRM: emotional dysfunction with anxiety; nervousness; irritability; financial doubts; clinical symptoms include fatigue and pain. In the period of four years survival after treatment we can observe divergence of psychosocial morbidity symptoms.

Our results show that the degree of psychosocial loads and quality of life is dynamic and qualitative differentiated process - in some parameters increased manifestations of emotional and social disorders. The outcome of this changed quality of life is: feeling of loss my, me., loss of personality value; change of personal features; changes in partnerships; emotional disorders. All these changes result in: evolution risk behavioral profile; social isolation; loss of ability to face cancer. Our analyses confirm that more than 70% of survival patients with breast carcinoma progressively emulate with consequences of cancer.

The feeling of loss of femininity decreases; feelings of loss sexual function disappear; physical and family functions are emulated. On the other side, in many of these patients: increased feeling of doubt; nervousness; irritability and it is graduated. This process of dynamic psychosocial loads is potentiated by permanent weakness and clinical symptoms which are undesirable consequences of treatment (pain, arm fibrosis, gastrointestinal disorders, insomnia). Risk behavioral profile of survival patients which is evolving mostly in young patients and psychically unstable women contains disorders in cognitive and behavioral spheres.

### Psychosocial support

Sources of social support are in Table 1. Most patients ( $\geq 75\%$ ) wanted and got social support from physicians and friends/family. Other sources of social support were not so wanted and rarely gotten. All types of social support were for women extremely helpful. The most helpful sources were physicians, nurses, and friends/members of family. The right column of Table 1 is related only for women who got only this type of support. Between these variables of social support and summary score EORTC QLQ-C30 there were not statistically significant relation.

**Table 1** Frequency of social support

	Support required	Support accepted	Support successful
Physician	72%	79%	97%
Psychologist	34%	15%	92%
Social worker	8%	3%	66%
Clergy	18%	9%	86%
Nurse	29%	7%	86%
Friends / Family	70%	78%	98%

### Discussion

Similarly, as in other European countries, patients with breast carcinoma are the largest group of survival persons with carcinoma diseases. 2,000 new diagnosed carcinomas every year means, that in 5 million population every year an increase number of patients who live in fear and doubt for the future. They have feelings about threat of untimely death; loss of femininity; frustration; other emotional disparities which funda-

mentally decrease quality of life. Ganz *et al.* (3), Holzner *et al.* (7) and other authors in extensive clinical studies show, that psychosocial loads from diagnosis and treatment of breast carcinoma decrease until one year after the end of treatment, but in some part of patients still for long time. Psychosocial morbidity has negative influence on quality of life and negative influence for average survival period (8). Patients, who live in long time doubt, frustration and depression, very often are isolated from natural social bonds and stay in social isolation. (9, 10). All these facts have negative influence on their quality of life; ability to face cancer with its negative consequences (1). Healthcare providers give emphasis on clinical parameters of healthcare (success of treatment; side effect of curative treatment; average period of survival). They don't give attention to psychological and social consequences of cancer in its all over trajectory - from diagnosis until end of treatment and follow dispensaries. Anxiety and depression are normal, part of the cancer process for them

Patients are dependent for emotional support which they search for in family or psychologist. In contrast with us, in the most advanced European countries, also in USA or in Australia, there are complex psychosocial systems of healthcare. Specialized oncological social workers provide psychosocial support. They are targeted, professionally prepared and are part of a caring team (11). European studies from Italy (12), Greece (13), Spain (14) and Turkey (15) found worse levels of QoL in breast carcinoma patients. While a study from Holland had a better level QoL. (16). A moderate score from a Brazil study (17) was like our moderate score.

One of the possible reasons, why there were reported only mild damages of life quality, can be the bias against selection. Women from high society were more included, because they had better chance of treatment in hospital, which was in study. It can be a reason for better quality of life. Another Columbian study of breast cancer patients found that a higher degree of education is connected with higher a quality of life (18). Treatment modes didn't have statistically significant influence on QoL. Extensive research, with more than 1,000 breast cancer patients (19), didn't demonstrate significant differences in quality of life because of the kind of treatment:

radiotherapy, chemotherapy or hormonal therapy. This does not mean that these therapeutic modalities don't have an influence on quality of life.

There is optimism connected with QoL. Every function scale were positive correlated with subscale of optimism LOT-R and 6 from 9 scales and items of symptoms were negative correlated. The highest correlation was found by generally evaluated health/quality of life ( $r = 0,31$ ). These positive associations between optimism and quality of life are demonstrated also in the common population (20). Religions and personal features were proved as mediator of relation between optimism and prosperity (21). We were not able to test the role of these mediators in our study. Except for correlations with QoL it is interesting that average score of patient optimism was not lower, but in actuality was higher than in the common population. Also, other studies demonstrated similar results. Average score of LOT-R in the groups of patients with breast carcinoma was between 16.2 and 16.9 (22, 23), which is higher than the average score in common European population. A German study found that patients with cancer want and really get social support from physicians and family/friends. Other specialists (psychologists, social workers, pastors) are engaged less (24). Physicians must know that they are not only specialists for patients, but patients hope for psychosocial support many patients were pleased because of physicians' support. But only half of patients who want this support actually got it. It is necessary to reconsider and evaluate barriers to another possibility of care. Integration of short time forms of monitoring of life quality in daily clinical routine can be a highly effective form for detecting physical and psychical disorders and their monitoring in time.

## Conclusion

The degree of psychosocial mortality in survival patients one year after MRM in our group clearly demonstrated that these patients are suffering because of consequences of psychosocial loads. This results from fear of recurrence of cancer and next functional, emotional, cognitive, and social disorders without regard for surgery range. The degree of psychosocial loads in patients after MRM is still more than 4 years after end of treatment. Results show that after end of treatment

there are many changes in their life: anxiety and depressions can lead to psychical lability because of: higher doubts; nervousness; irritability; helplessness; loneliness in their sufferers. It is clear, that without adequate psychosocial intervention there is still symptomatology of psychosocial morbidity. It means that quality of life is inferior; the results of treatment are worse; ability to face to cancer is less. Results of our study confirm urgent need for prevention of psychosocial distress which relates to cancer with adequate forms of professional psychosocial interventions.

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# Teaching Learning Methodology in Times of COVID-19 Pandemic: A Case Study

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## Abstract:

The Education system in India underwent a major change due to the sudden lockdown announced by the Government in view of COVID – 19 pandemic. Both teachers and students had to shift to online mode in a very short time period. The present study analysis the positive and negative aspect of this online mode of education and measures adopted by teachers to maintain the flow of education along with attendance. The survey was conducted at JSS Academy of Technical Education, Noida. More than 100 teachers and students participated in the survey conducted. Also experienced faculty came up with suggestions and ideas to improve the online mode of education in view of such pandemic situations. Two teachers who were also

teaching kids at an NGO school running in the campus premises shared their view on what efforts they took to let education reach the kids at the NGO as digital divide was the main problem there. Such findings will help in designing a future teaching model to cope with pandemic situations and not let education suffer.

## Introduction

The sudden outbreak of Corona Virus almost brought the whole world to a standstill. (Ben Hu 2021, Aditi Madan 2021). Seeing its rapid spread and scare to human lives WHO (World Health Organization) declared it a global pandemic (Domenico 2020). Sudden closure of schools and colleges forced the Teaching Learning procedures to shift to online mode completely. (Luca Botturi 2020, Kapasia 2020, Owusu 2020). It was a very tough and challenging task for both teachers and students. (Affouneh 2020, Favale 2020, Todorova 2011). As teachers had to impart education so that student's career did not suffer and their whole year was not wasted while student's had to switch over to online mode as no other option was left in such pandemic times. The biggest challenge with teachers was to keep the teaching spirit alive among students especially those with poor financial conditions, since the biggest challenge with these students was if their studies got a break they would be compelled to return back to a family business which included sitting at shops, household works, robbery, etc.

The present study focusses on understanding the problems faced by Teachers and Students during the lockdown as far as online education is concerned. (Agarwal 2016). The over all aim of the study meant to analyze the measure's teachers and students adopted to keep their education running.

From ancient times, Teaching Learning has been an interactive field where in the teacher and student interact in person. This major feature was at drawback with online mode of education which is technology based. But, due to the lockdown it seemed to be the only solution for the system to keep running. (Shivangi Dhawan 2020). Since, online mode of education is the only option in this time of pandemic where the entire world is forced to sit at home (Al-Fraihat 2020, Arinto 2016). With online mode of education relying on the Internet it is the only way to make education reach every corner of the country

as students have migrated to their hometowns in view of lockdown. (Cascio 2016). This mode of teaching on a virtual platform has, both the good and bad. (Cidral 2018, Islam 2015). The best part being it allows flexibility of timings, place, format of lecture delivery which could be a recorded one; power point presentation; lecture by national/international speaker, etc. both for the Teacher/Student giving more exposure to the topic, instead of the usual classroom type where students are bound to have a single teacher in class and follow protocols of timing and place. (Andrew 2013). No doubt, few foundations are there like judgement of students performance with an examination system coming on online platform and students giving exams from home sitting in front of their own system, cannot be matched with the traditional way of examinations which were bounded with center; timing; invigilation by examiners; no carrying books or notes to center; etc. But seeing the pandemic situation (Per Engzell 2020) it is the only way out or else students will be at a loss with wastage of their academic year. (Megan Kuhfeld 2020)

### The specific objective of the study was

- To identify, the problems being faced by teachers and students both when going for an online mode of education.
- To identify the tools and techniques for Teaching Learning methodology which were user friendly.
- To identify the syllabus coverage and how much students were able to adapt and how they managed their practical work.
- To suggest methodology for designing future models of education, especially for pandemic times keeping in mind that such lockdowns become a part of lifestyle.

After compiling the survey results and short listing the genuine problems being faced by them, the problems were discussed with experienced teachers of JSS Academy of Technical Education and the present study made an effort

to find a solution for the same. The future scope of this work will help in planning of Teaching Learning methodology which are suitable for future pandemic situations. Policy makers will benefit with the suggestions given by both teachers and students in the survey for smooth conduct of online classes in times of pandemic.

### Study Area

This study was carried out at JSS (Jagadguru Sri Shivarathreeshwara ) Academy of Technical Education, Noida which is a private engineering college, affiliated to Dr. A.P.J. Abdul Kalam Technical University situated in Sector 62, Noida. Noida, a planned city is located in the Indian state of Uttar Pradesh, district Gautam Budhh Nagar. The Institute has a large student strength of over 3,000 students and more than 200 faculty members. This study can set an example for other Institutes to follow as far as Teaching Learning Methodology is concerned, especially in such a pandemic situation which has arisen because of COVID-19 lockdown (Lokhnath Mishra 2020).

The survey was conducted in the first 2 weeks of August, 2021 when teachers started reporting to campus for their duties and students came in batches either to vacate hostels, issue books from library, get practical files signed or for clearance of any type of doubts from teachers or any other administrative purpose. This is an academic research to estimate the challenges in online mode of education faced by both teachers and students studying or teaching at JSS Academy of Technical Education, Noida when the whole mode of education shifted to online mode in view of lockdown due to COVID – 19 pandemic. The study was conducted, employing a questionnaire prepared using 'Google form'. An aggregate of 200 students and 180 teachers participated in this survey.

The questionnaire consisted of 2 paragraph based questions where both teachers and students were free to write any suggestion or comment (keeping their identity anonymous) as questionnaire did not ask questions of name and email id compulsory. These suggestions which have been given with free mind have been discussed and will pave the way for planning of a future model of education.

The academy switched to an online mode of

education completely during the second lockdown when both Teachers and Students had to explore technology options to keep their education process running smoothly. No doubt it gave more time to the Teaching Learning field to experiment with new techniques and ideas for online mode of education. So many virtual platforms came up, all of a sudden demand for smartphones, laptops, Internet connectivity, microphones, speakers, etc. came up (T. Muthuprasad, 2021). The technology market no doubt got a boom in this time of pandemic when other fields like tourism, travelling, eating outlets had major setbacks due to lockdown.

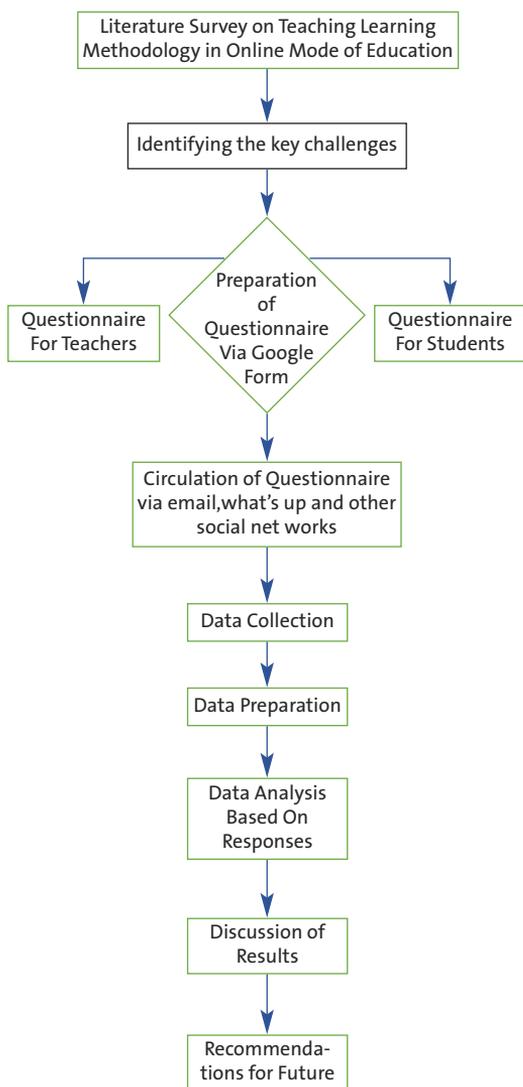
(Eileen Bridges2017).

### Methodology

Two 'Google Forms' consisting of questions relating to challenges, strengths, weaknesses , technology, time to switch to online mode of education, etc. was created after discussion with experienced faculty members of the institute and literature survey. Two Google forms were circulated one for teachers and one for students via email and *What's Up Groups* and Google Classroom of their respective classes and other social networking sites. Gentle reminders to teachers were given via email after one week in case any of them were pending. Students were reminded also after a week's time via Google Classroom, email and *What's Up Groups* created for every branch and section. The students were the one's pursuing B.Tech (in any branch) belonging to the undergraduate stream and telephonic conversations with students who were coming in the NGO classes run in the Academy (before lockdown) for the children from poor family background.

The questionnaire was created in English. Methodology for this study is depicted in Figure

1. The details of the questionnaire and the response data obtained are tabulated in Table 1.

**Figure 1** Methodology Flow Chart

Both the Google forms consisted of 22 questions – 20 multiple choice questions and 2 paragraph based to help identify measures to be taken to improve online education in schools and NGO run by social workers. Each multiple choice question had an option of “other” so that the teacher or student could freely add their option in case missing. A Google form titled “Questionnaire For Teachers” with 20 Multiple Choice Questions and 2 paragraph based were circulated in JSS Academy of Technical Education, Noida (India). **Questions 1 & 2** which asked name and email were not kept compulsory in order to pro-

tect privacy and let one answer the questions with free mind, especially students without fear of getting noticed. All the rest of the questions from **Question 3** till question 20 (MCQ) were kept compulsory in order to identify the strengths, weaknesses and future aspects of online mode of education for both teachers and students. A 3<sup>rd</sup> question was of age group starting from 26 years till 60 plus, as many teachers in NGO are the younger ones between 20 to 30 years of age group. **Question 4** was based on years of teaching experience, this would give a more clear picture of how useful experience is in picking up online mode of education. **Question 5** identified the category of students being taught by that specific teacher i.e. whether undergraduate (pursuing B.Tech), post graduate (pursuing M.Tech or PhD) or the ones being taught in NGO run in the institute premises. This will help in understanding the difference in efforts made by teachers when category is concerned. **Question 6** surveys where teachers are being asked to identify the students on the basis of their family income will help in giving an idea to the teacher that to what level the student can afford technology for online classes, categories given here were lower income, lower middle, upper middle and high. With online education, it was felt necessary to know whether the teacher is getting a separate place to conduct his/her online classes as teacher has to interact with a large number of students and usually as per practice they raise their voice while delivering lectures or solving queries of students, in personal room a teacher freedom to interact with students without disturbing their family members, hence in, **Question 6** asks whether the teacher has a separate room to deliver his /her lectures. **Question 7** is the most important question, where the teacher has been asked what mode he/she is using while delivering lectures all possible options have been included for same. Since, teachers were given very short notice for start of online classes, **Question 8** gave them a chance to tell how much time they took in switching over from chalk mode to online mode and balancing their work and family life together an analysis of this question will help the institute in deciding in future how much time should the teachers be given to prepare for online mode and come out with their best for the students.

Many teachers in the beginning were in a dilemma over whether they would be able to switch over to online mode or not, especially the ones who were not very technology friendly, hence the next question gives them a chance to let know what technology problem they suffered most, so that in future some solution can be found for same or the teachers be updated about it through a webinar or talk. One question each on weakness and positive aspect of online education was asked with options which are general with teachers were given.

Since, there are so many platforms of delivering lectures next question asked was, which specific platform the teacher found convenient as per his/her situation. Major online platforms were mentioned in the options. Since, the second wave of the COVID pandemic was a very severe one with almost every 3rd house having a tragedy, it was very necessary for a teacher to keep the human aspect also while teaching, hence question focusses on the human aspect given while teaching students, so that the pandemic does not have a even greater impact on their studies and they at least attend their classes. The next 3 questions, focused on the methodology aspect of teaching. In **Question 15**, the teacher has been questioned about the methodology adopted for lab/field work especially data handling and in question sixteen an update is taken from teacher regarding the technique they are adopting to increase or maintain a good strength of attendance in their class, this is very important aspect as many previous surveys have reported the problem of short attendance in online mode of education. The correct answer to this problem will help teachers solve the problem of short attendance.

Since, a teacher has to prepare his/her lecture beforehand, especially when online mode is considered it is necessary to get an idea of the time taken by the teacher on a daily basis for preparing his/her next lecture as many teachers especially the ones teaching small kids in NGOs have to prepare colorful, animated lectures to attract the attention of small children an idea of its time consumption is very important. **Question 19** takes a general feedback from teachers to what type of lecture kept the students engaged, this question can truly only be answered by those teachers who took their classes regularly and monitored the attendance of the students. Last multiple choice

question is about stating the biggest disadvantage of online education, though in this time of pandemic online education is the only solution, but still an answer to this question can help improve the disadvantage. From **Question 3 to 20** (MCQ) all questions were given the option "other" so that, in case anyone has any other option which has not been mentioned then they can state it. The last two **Question 21 & 22** have been kept paragraph based and NOT compulsory so that views can be expressed freely. Question 21, gives the respondent freedom to give suggestions to improve the online mode of education, and lastly 22 another paragraph based question openly asks for any type of feedback.

### Questionnaire for Students

Based on similar pattern as that of teachers, a questionnaire for students was prepared with few variations. The age group in case of students was lowered and range was kept between 5 to 25 years. Lower age group was meant for NGO kids, while the ones above 18 for undergraduate and postgraduate students was kept. Minor change was done in Question 18, wherein students were asked about how much time it took them to solve the quizzes and assignments they were receiving. Rest of the pattern was similar as that of teacher's questionnaire.

**Table1**

Parameter under Study	Teacher's Responses (%)	Student's Responses (%)
<b>Age Group</b>		
Above 15 years	0%	44%
Above 20 years	0%	56%
Above 25 years	-	0%
Between 26 - 31 years	20%	-
Between 32 – 38 years	44%	-
Above 40 years	26%	-
Above 50 years	10%	-

<b>Category</b>		
Undergraduate	82%	83%
Postgraduate	12%	9%
NGO	6%	8%
<b>Gender Distribution</b>		
Female	48%	28%
Male	52%	72%
<b>Family Income Status</b>		
Lower Income	6%	18%
Lower Middle	42%	39%
Upper Middle	50%	43%
High	2%	-
<b>Separate Room for Studies</b>		
yes	76%	46%
no	24%	54%
<b>Mode of Attending Online Classes</b>		
Desktop	4%	2%
Laptop	94%	50%
Tablet	-	4%
Smart Phone	2%	44%
<b>Time Taken In Balancing Home/Work</b>		
1 week	60%	17%
2 week	22%	11%
3 weeks	6%	15%
More than 3 weeks	12%	57%
<b>Technology Drawbacks</b>		
Downloading errors	12%	6%
Issues with installations	14%	15%
Log in problems	16%	20%
Problems with audio/video	48%	59%
others	10%	-
<b>Strength with Online Teaching</b>		
Flexibility of location	50%	48%
Flexibility of time	24%	28%
Interaction with larger groups of students	16%	4%
Saves cost	4%	20%
others	6%	-
<b>Weakness of Online Education</b>		
Time Management	8%	11%
Technical Difficulty	18%	24%
Distractions from home front	8%	30%
Face to face interaction with whole class missing	64%	35%
others	8%	

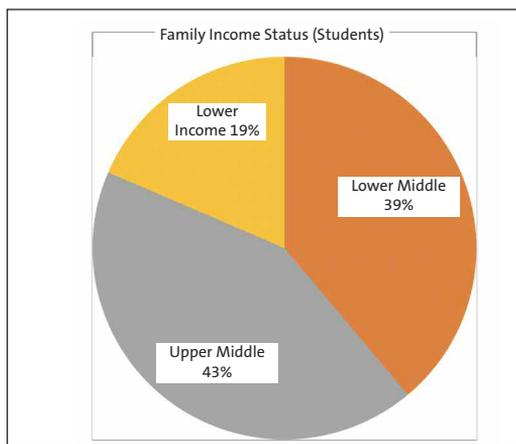
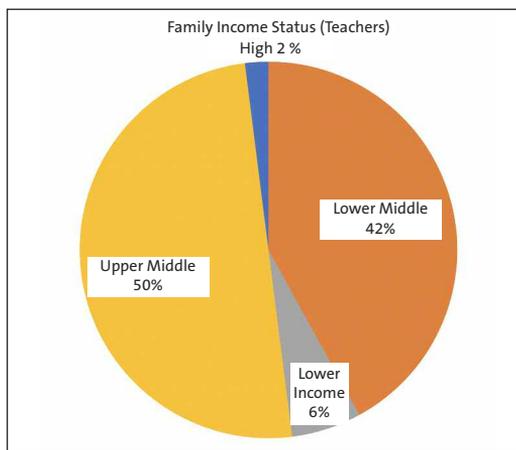
<b>Positive Aspect of Online Education</b>		
Designing flexible programs	14%	8%
Scope for digital development	34%	24%
Various formats of lectures	32%	13%
Saves time of travelling to college /school	12%	48%
others	8%	7%
<b>Most User Friendly Platform</b>		
Zoom	78%	72%
Microsoft teams	8%	4%
Google meet	12%	24%
others	2%	-
<b>Efforts To Maintain Human Touch to Lectures</b>		
Motivation given by teachers from time to time	52%	41%
Free interaction with teacher on personal issue	10%	22%
Flexibility in timings of class	-	9%
Study material provided separately	24%	28%
others	14%	-
<b>Percentage of Curriculum Covered</b>		
100%	58%	35%
Between 80-100%	30%	33%
Between 60%-80%	12%	20%
Below 50%	-	12%
<b>Methodology Adopted for Lab/field work</b>		
Used data of secondary source	12%	15%
You tube videos available for experiments	24%	48%
Virtual lab links used	56%	24%
Only theoretical aspect of experiment updated	6%	13%
<b>Number of Hours Spent Daily in Preparing/ Solving quizzes/ Google forms etc.</b>		
1-2 hours	44%	46%
3-4 hours	46%	22%
4-5 hours	8%	4%
Less than 1 hour	2 %	28%

Project/Assignment Lecture Most Engaging for Class		
Self recorded video lectures	24%	19%
You tube videos	14%	20%
NPTEL lectures	18%	11%
Lectures from international speakers	6%	4%
Assignments given via Google forms	26%	35%
others	12%	11%
Disadvantage With Online Mode of Teaching		
Created a sense of isolation	4%	13%
Missed face to face direct interaction	40%	36%
Fair judgement of students performance not possible	40%	13%
Technical Failure	6%	30%
not possible to move to digital content (by Students)	10%	8%

Once the deadline of two weeks was over, the response link was closed and Google form of both teachers and students was downloaded as Excel. A total of 120 responses of teachers were there followed with 149 responses of students. After checking the responses invalid and incomplete entries were excluded and 100 entries of teachers and 108 entries of students were finalized for further studies. In addition to this, 2 Teaching Learning students of NGO were spoken on phone as they were not coming to campus and showed inability in filling the Google form, along with suggestions of experienced and senior faculty members taken for improvement of the Teaching Learning Methodology in lockdown.

### Results and Discussions

A total of 52% male and 48% female teachers; 28% female and 72% male students. The survey further took a look at the age groups of teachers and students as the academy comprises of teachers of all age groups. 10% of teachers were in the age group above 50, giving the survey a chance to take advantage of the experience of these senior faculty members which can help the younger teachers. 26% of teachers were in the age group of above 40; highest percentage 44%

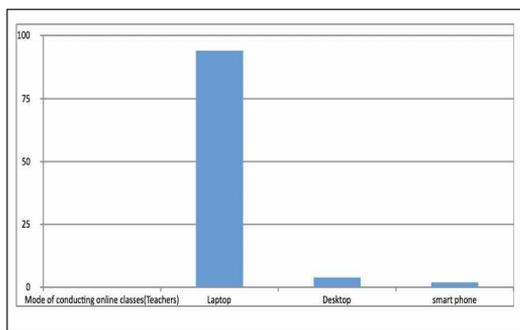


of middle age group teachers 32 to 38 years of age; while 20% between the age of 26 to 31 years. Student age group comprised of majority strength of 56% above 20 years the ones pursuing B.Tech (Bachelor of Technology) from the institute and belonging to the 3rd year, 4th year or post graduate programs; 44% above 15 years of age comprised of B.Tech 1st year students and NGO kids. The family income status Figure 2, was also looked into before starting the survey because online mode requires electronic gadgets, which generally are not possible for students to purchase if they come from very poor family backgrounds, especially the NGO kids. The survey showed that majority strength of teachers belonged to the upper middle income group 50% which made it possible for them to afford Laptops, Stable net connection, smart phones, writing pads etc. for smooth conduct of classes during lockdown. 42% belonged to the lower middle income group; 6 % belonged to the lower income; 2% to the high income group.

With students, also a similar result was obtained where 43% belonged to the upper middle class; 39% in lower middle class; 18% in the lower income group which were the NGO kids.

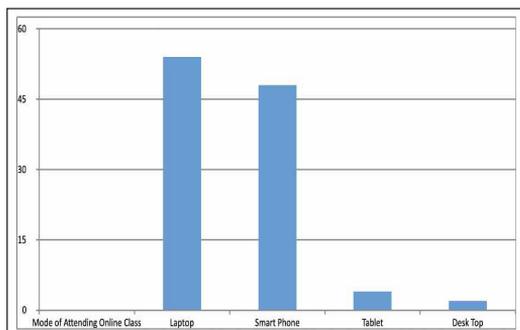
Going into depth of survey it was asked whether both students and teachers have a separate room to study: 76% of teachers had a separate room to take online classes; 24% did not. While 54% of students did not have a separate room to study; only 46% had one. This could be attributed to the fact that since teachers are earning and in higher age group compared to students and probably residing in their own residences, they have a separate room, but students must be sharing their study room with their siblings or other family members.

**Figure 2** Author Survey Family Income Status



When questioned about the mode of conduct of online classes, 94% of teachers used Laptop; 4% using desktop; 2% using smartphone. With students small variation in results was seen with 50% possessing a Laptop; followed by 44% with smart phones; 4% had Tablet; 2% a desktop. Higher ratio of smart phones with students could be because of sudden lockdown announcement by Government they

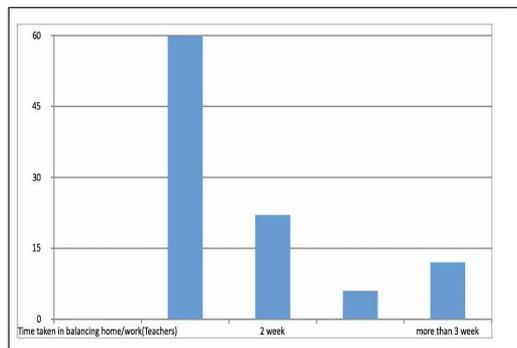
**Figure 3** Mode of Conducting Classes



could not possibly afford a Laptop in such a small time, hence keeping the family budget in mind they compromised with a smartphone. Giving an option to teachers to choose mode of lectures which are easily accessible on smart phones and quizzes /assignments etc be designed such that students can solve them on smartphones.

Next question asked was how much time both teachers and students took in balancing studies from home. It was found that 60% of the teachers took less than a

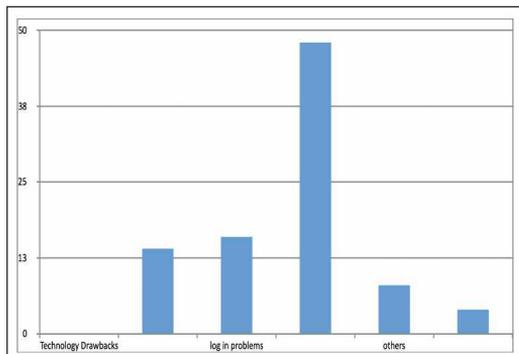
**Figure 4** Time Taken to Switch Over



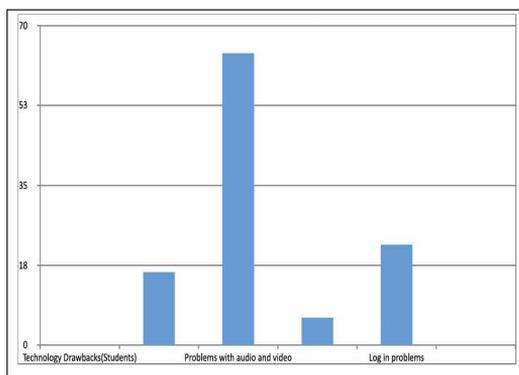
weeks time to settle down: 22% took 2 weeks may be they arranged the Wi- fi or Network for smooth conduct of the classes; while 12% took more than weeks in arranging the same; 6% took three weeks.

The survey results of students showed that it took them longer time compared to teachers in balancing the attending of online classes: 57% took more than 3 weeks; reason could be with sudden announcement of lockdown these students had to vacate the hostels and rooms taken on rent and travel to their home town which was time taking; followed by 17% students who took less than a week because of being local candidates and availability of stable net connection along with laptop or smart phone at home; 15% took 3 weeks; 11% took 2 weeks.

**Figure 5** Drawback of Online Education

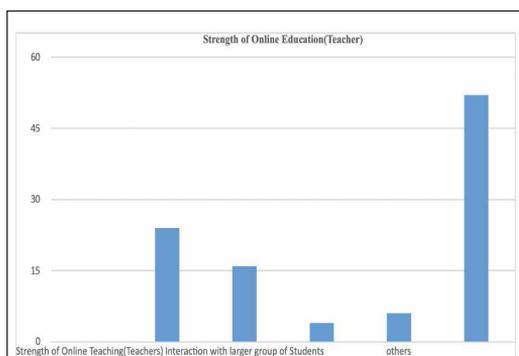


**Figure 6** Drawback of Online Education Students Teachers

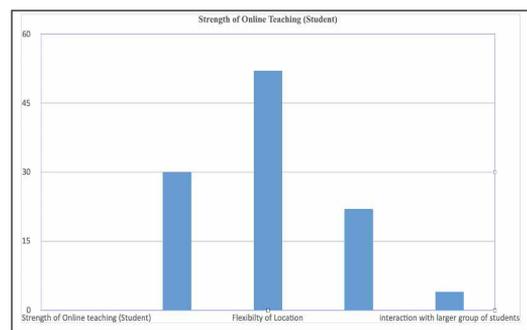


As is clear from the bar charts Figure 5 and 6, both teachers and students suffered problem of audio and video during online classes which seems to be their major technology drawback. Followed by other issues of log in problems: 16%, had issues with installations; 14% with teachers; followed by 12% downloading problems: with students 20% had log in problems; followed by 15% with issues of installations and 6% with downloading errors.

**Figure 7** Strength of Online Education (Teachers)



**Figure 8** (Strength of Online Education Students)



When questioned about the strength of online teaching both teacher and student came up with maximum response for flexibility of location; both Figure 7 and 8 gave a 50% positive response for the same followed by flexibility of time with 24% teachers agreeing to it and 28% students. For the option of saving cost with online mode of teaching students positive response was more than 20% compared to teachers who gave only a 4% response to the option; this could be attributed to the fact that teachers are earning and finance is not a constraint for them, but for students finance seems a major constraint when switching over to online mode of education.

On weakness of online teaching both teachers and students gave a thumbs up for missing face to face interaction with 64% teachers and 35% students agreeing to this point; followed by 18% of teachers suffering technical difficulties and 8% distraction from home front. The results varied for students when distraction from home front was considered as 30% students suffered the distraction from their home front, maybe because they did not have a separate room to study.

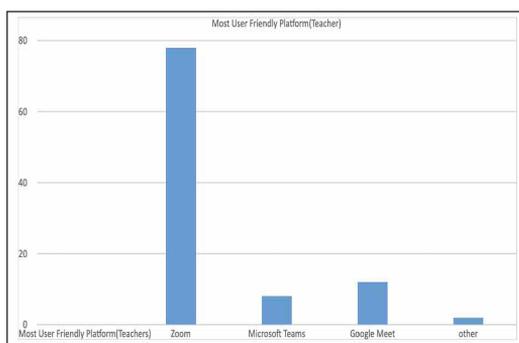
When questioned about the positive aspect of online education 34% of teachers agreed to the fact that it had scope for digital development, followed by 32% agreeing to ease of various formats to deliver lectures. But when the question was raised to students their responses varied, with a maximum number 48% agreeing that it saved time of traveling to school college; followed by 24% agreeing to the scope of digital development; 13% agreeing to various formats of lectures. It seems, once again the cost factors play a major role in judging the positive side of online education.

For the question of most user friendly platform for online mode of education it seems Zoom

emerged the winner with both teachers and students giving it the highest vote: teachers voted 78% for Zoom, followed by 12% for Google Meet, and 8% for Microsoft Teams. While students gave a 72% response for Zoom, 24% for Google Meet, and 4% for Microsoft Teams.

Zoom platform (Figure 9) seemed to be the most popular among both teachers and students. Zoom platform found its popularity because of ease of application; availability of app on smart phone; easy creation of meeting link; user friendly mode of operation.

**Figure 9** Most User Friendly Platform



With online mode of education the only option in the time of pandemic caused due to COVID-19 where many people lost their lives especially in the 2<sup>nd</sup> wave with every 2<sup>nd</sup> house having a tragedy due to the deadly virus it was very challenging to maintain a human touch to education while 52% of teachers agreed they kept motivating their students emotionally in between lectures on daily basis so that students do not lose touch to studies and land in depression; 10% of teachers called up students after class to speak to them personally and motivated them not to lose hope. Similar responses were obtained from students where 41% agreed to getting motivation from their teachers in this time of pandemic; 28% agreed to extra efforts made by teachers in providing notes and other class material which they missed due to tragedy; 22% agreed to the extra time given by teachers.

On the syllabus front, 58% of teachers managed to complete their prescribed curriculum timely; while 30% managed between 80% to 100%; 12% between 60% to 80%; these were the ones teaching the NGO kids where in the students coming in classes run by the NGO group

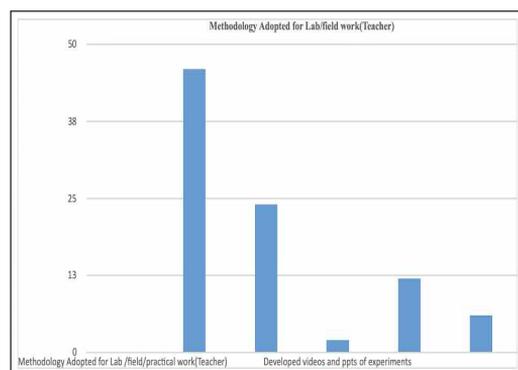
failed to a great extent in switching over to new technology because of which their basic syllabus suffered.

As far as the students were concerned 35% only managed to study their full syllabus; 33% between 80% to 100%; followed by 21% between 60% and 80%; followed by 12% of students who managed to complete below 50% of their syllabus.

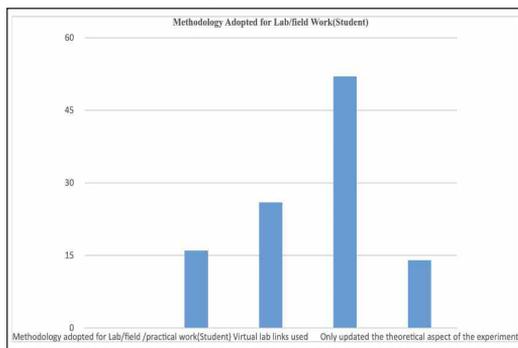
The next question was the number of hours spent on a daily basis by teachers in preparing their lectures for online mode, Google forms, quizzes etc. which they were giving students on a daily basis, 46% teachers on an average took 3 to 4 hours; followed by 44% who took between 1 to 2 hours; 8% took 4 to 5 hours maybe because of unstable internet connectivity; 2% took less than 1 hour because of all available resources. While 46% of the students managed to solve their quizzes, etc. in 1 to 2 hours; followed by 28% who took less than 1 hour; 2% 3 to 4 hours; only 4% took 4 to 5 hours maybe they must be engaged in house work or having less net connectivity.

Since, almost all courses required lab work teachers and students were asked about the methodology they adopted for it. Figure 10 & 11: 56% of teachers agreed to using virtual lab links provided by AKTU (Abdul Kalam Technical University) on their website; 24% agreeing to showing *youtube* video links available on site; 12% used data of a secondary source; 2% updated students with theoretical aspects of laboratory work. Student analysis showed that 48% relied on available youtube videos; 24% used virtual lab links provided by AKTU; 15% used data of secondary source; 13% updated themselves with the theoretical aspect of the experiments.

**Figure 10** Methodology Adopted for Lab

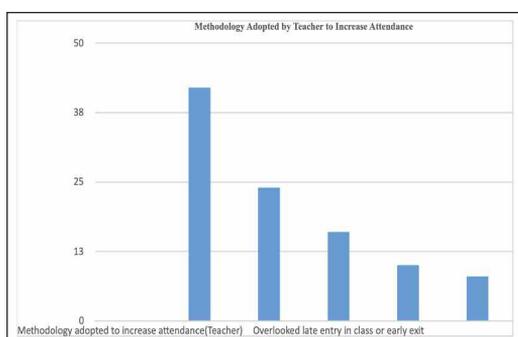


**Figure 11** Methodology Adopted For Lab (Student)



When questioned about assignment found most engaging for class both teachers and students voted maximum for Google forms prepared on daily basis followed by recorded videos of teachers, *youtube* videos and because of easy contact with experts NPTEL lectures also found space in students survey. Once again when questioned about the biggest disadvantage of online mode of education both teachers and students agreed to missing direct face to face interaction followed by technical failure and creation of a sense of isolation.

**Figure 12** Methodology Adopted by Teachers To Increase Attendance



Lastly one extra question was asked from teachers for the methodology they adopted to maintain attendance in class, because at one stage online education becomes very monotonous and attendance of students starts to gradually decrease. 42% of teachers adopted a very friendly behavior with students so that they do no fear to attend classes; 24% agreed to giving simple quizzes and assessment sheets to students; followed by 16% who overlooked factors like timings of

entry and exit in class; while 8% rewarded their students with good attendance in the form of e-certificates,

Additional marks in internal assessment, etc. These findings can be of great help while designing future models of education in such pandemic times.

## Conclusion

As per findings of this survey certain suggestions for policy makers are:

- Separate small study room can be had while designing hostels for students with Internet Connectivity since majority of students did not have a separate room to study.
- 44% of students used smartphones as they could not afford a laptop, in near future students with good performances can be rewarded with laptops.
- Since more students are using smartphones teachers must ensure that all educational apps which they are using for teaching should work on mobile phones also.
- Time duration of lectures be reduced as students complained about bandwidth getting consumed more due to larger duration of lectures.
- Students who cannot afford conveyance charge to college daily for attending classes can be permitted to attend the same via online mode.
- Lab Instructors be given special training to demonstrate practicals and prepare videos of same which can be uploaded on site for students.
- A free webinar can be conducted on regular basis for both teachers and students to update them of new technology and solve their issues related to digital divide.

Findings of this study and the suggestions given on its basis can help develop competencies in both teachers and students and help them face the problem of digital divide, which will help them in smooth conduct of their education in future pandemic times. These findings offer some early indications to policymakers and school leaders that the experience of distance/online teaching and learning, although challenging, may have lasting positive effects, opening up interesting possibilities for innovation and new ways of working, especially if supported by appropriate and timely professional development.

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# Importance of Midwifery Care in the Prevention of Postpartum Depression

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## Abstract:

**Introduction.** This article focuses on the importance of midwife care for women in the puerperium period for the prevention of postpartum depression. This care is mostly preventive; therefore, education occupies an important place. Using appropriate education and preventive strategies, many complications or problems, such as postpartum depression, can be minimized or recognized in time.

**Methodology:** The research method was a controlled nursing experiment. The essence was to compare two different groups and find to what extent the care of a midwife contributes to the prevention of postpartum depression. The experimental group consisted of 100 women with the care of a midwife in the puerperium period, where three visits took place during the puer-

perium period, throughout which the Edinburgh Postpartum Depression Scale EPDS was used to assess mental health. The control group consisted of 100 women without the care of a midwife in the puerperium period. A questionnaire was sent to these women at the end of the sixth week, along with an EPDS scale.

**Results:** A statistically significant correlation was found between the risk of postpartum depression and problems with neonatal care ( $p = 0.016$ ). There was also a statistically significant difference in the incidence of problems with newborn care according to the presence of a midwife ( $p = 0.005$ ) and midwifery care in the area of breastfeeding ( $p = 0.049$ ). The distribution of the results of the EPDS scale did not differ statistically significantly ( $p = 0.775$ ) depending on the care of a midwife.

**Conclusion:** The results showed that the care of a midwife leads to the prevention of health complications in women in the puerperium period. The care of a midwife does not lead to the identification of postpartum depression more often, but symptoms are recognized earlier, and treatment is started. A midwife's care can also reduce the predisposition to postpartum depression. Women attended to by a midwife showed fewer problems with breastfeeding or newborn care, which are two of the predictors of postpartum depression risks.

## Introduction

A midwife is a non-medical health professional who provides primary care during pregnancy, childbirth and the puerperium period for physiological women and newborn babies. A midwife plays a significant role during the postpartum period, when a woman comes home with a new member of her family after giving birth. A midwife is able to provide both health services and, especially in the postpartum period, important psychological support. Through their care and presence, a midwife contributes to reducing maternal and neonatal morbidity and mortality (1). Most women in the Czech Republic, mostly primiparas, come home from the maternity hospital after 72 hours and cannot imagine taking care of themselves and a newborn baby. The most common problems that occur in the puerperium period are problems with breastfeeding or care of the newborn baby. The woman's psyche is also exposed to great strain. Firstly, due to hormonal and physical changes, but also due to adaptation to the new role of the mother. Mood swings during the puerperium period are common. However, if mood deterioration is pro-

longed and is accompanied by anxiety, fear, helplessness, or loss of interest and pleasure, it can result in postpartum depression (2).

Postpartum depression is a worldwide problem. Globally, up to 150 women per 1,000 live births suffer from depression (3). The worldwide incidence of postpartum depression is around 10-15%. However, it is clear that the prevalence of postpartum depression can range from 0 to 60% depending on various influencing factors (4). A systematic review of 291 studies from 56 countries indicated an even higher prevalence of postpartum depression of 17.7% (5). However, the incidence of postpartum depression can also be affected by the frequency of its testing.

Postpartum depression affects a woman's life, her whole family, but also the child's development. In some cases, depression can grow into postpartum psychosis. In the Czech Republic, postpartum depression is not adequately addressed. This is a problem about which pregnant women and women in the puerperium period often have no information. There are no large numbers of self-help groups or organizations in the Czech Republic. The highest numbers of

women suffering from postpartum depression meet in discussion forums where they go for advice concerning their children. According to research, the prevention of postpartum depression includes intensive and professional postpartum care (6) provided by a midwife during the puerperium period.

Community care provided by a midwife is not a service commonly utilized in the Czech Republic, although its benefits are well-known. The care provided by a midwife is still seen as above standard, for which women have to pay extra money in most cases, because cooperation with insurance companies and district gynecologists is not integrated enough. Women who do not have their own midwife seek help during the puerperium period from by district gynecologists, who often treat their problems with medication, although in some cases a thorough education and a change in the family's daily routine would suffice.

## Methods

**Goal:** Find to what extent the care of a midwife who uses preventive strategies in their work can influence the onset of postpartum depression.

Research cohort:

The research group consisted of 200 women in the puerperium period, who were deliberately selected. 100 women with the care of a midwife in the puerperium period in the experimental group and 100 women in the control group without the care of a midwife. The deliberate selection eliminated a serious medical history in a woman's history, including blood loss of more than 1,500 ml, TEN, pulmonary embolism, uterine rupture and perineal rupture of 3b grade during the delivery, which could distort the research results.

Methodology:

The method of research was a controlled nursing experiment. The essence was the comparison of the results within the experimental group of women and the control group of women. The experimental group included selected women in the puerperium period who were visited at least 3 times by a midwife during the puerperium period in a community setting. The women were informed about the goals of the research and signed an informed consent document. Standards of care were established to en-

sure the uniformity of care provided by each midwife. Each midwife also had documentation available. The control group included selected post-puerperium women who did not receive community care by a midwife. A questionnaire was sent to these women to their e-mail addresses which they had made available at the maternity hospital. The questionnaire focused on their: obstetric history; their newborn; the course of breastfeeding; physical and mental changes after childbirth; adaptation to the role of the mother; support from the environment.

The Edinburgh Postpartum Depression Scale (EPDS) was used to screen postpartum depression in all respondents. The EPDS was always distributed during the last visit by the midwife at the end of the puerperium period or sent to the e-mail addresses of the women in the control group. The scale has ten questions, including a question regarding suicidal thoughts. Scoring takes place on a scale from zero to three. In women who score higher than 12 and have never experienced postpartum depression, there is 86% sensitivity and 78% specificity for postpartum depression. Women must fill in the EPDS completely by themselves; EPDS is quickly evaluated by trained staff. With a score higher than 13 points, it is likely that a woman suffers from postpartum depression of varying severity. However, an assessment of the client's overall condition and clinical examination is also required to confirm the diagnosis. This scale assesses how a woman has felt over the past week. If recurrence is required, it is advisable to repeat the examination after two weeks (7). The total score is calculated by adding the circled numbers for all ten items together. The higher the score, the more likely it is that the person who completed this questionnaire is or may be depressed. It is only a monitoring tool that should not be used to directly diagnose depression.

Data processing:

Descriptive statistics (frequency tables with absolute and relative numbers) were used to describe the data. A chi-square test was used to test the monitored parameters. Statistical tests were evaluated at a significance level of 5%. Processing was performed by the program Stata v. 10.

## Results

The experimental group with the care of a midwife consisted of 100 women, mainly first-time mothers (69%), with a university degree (54%). The control group then consisted of 100 women without the care of a midwife during the puerperium period, mostly multiparas (60%) with secondary education (60%). The respondents were mostly women after vaginal delivery in both the experimental (68%) and control groups (77%). From the health point of view, women in the puerperium period; suffered prima-

rily from suture pain (37%); painful or bleeding hemorrhoids (16%) or an increased risk of postpartum depression (24%) in both study groups (Table 1). The group of women who had community care provided by midwives in their puerperium period included three women who had to seek medical help. The group where the women did not have community care provided by a midwife included eleven women who had to seek medical help, and three who needed a telephone consultation with a doctor.

**Table 1** Basic data

	Community care provided by a midwife n=100		No community care provided by a midwife n=100		Total n=200	
Demographic data						
	Absolute number	%	Absolute number	%	Absolute number	%
<b>Primiparas</b>	69	69%	40	40%	109	55%
<b>Multiparas</b>	31	31%	60	60%	91	45%
<b>University education</b>	54	54%	15	15%	69	35%
<b>Secondary education</b>	38	38%	60	60%	98	49%
<b>Elementary education</b>	8	8%	25	25%	33	16%
Method of delivery						
<b>Vaginal delivery</b>	68	68%	77	77%	145	73%
<b>Operational delivery (VEX, Forceps)</b>	5	5%	2	2%	7	3%
<b>Caesarean</b>	27	27%	21	21%	48	24%
Health problems during the puerperium period						
<b>Urinary incontinence</b>	1	1%	6	6%	7	3%
<b>Disintegration of birth injuries</b>	13	13%	2	2%	15	8%
<b>Suture pain</b>	40	40%	33	33%	73	37%
<b>Painful and bleeding hemorrhoids</b>	19	19%	13	13%	32	16%
<b>Breast inflammation</b>	7	7%	10	10%	17	9%
<b>Increased risk of postpartum depression</b>	26	26%	22	22%	48	24%

The research found a link between the risk of postpartum depression and problems with neonatal care (Table 2). A statistically significant correlation was found between the risk of postpartum depression and problems with neonatal care ( $p = 0.016$ ). Respondents at risk of postpartum depression had problems with neonatal care in 42% of cases, compared with respondents without risk of postpartum depression (24% of persons with problems with neonatal care).

**Table 2** Correlation between the risk of postpartum depression & problems with care of the newborn

Postpartum depression risk	Problems with neonatal care		Total
	Yes	No	
Yes	20 (42%)	28 (58%)	48 (100%)
No	36 (24%)	116 (76%)	152 (100%)
<b>Total</b>	<b>56</b> (28%)	<b>144</b> (72%)	<b>200</b> (100%)

Chi-square test,  $p = 0.016$

Depending on the results of the previous hypothesis, we were also interested in whether women cared for by a midwife in the puerperium period had fewer problems with neonatal care (Table 3). There was a statistically significant difference in the incidence of problems with neonatal care according to the presence of a midwife ( $p = 0.005$ ). In women cared for by a midwife in the puerperium period, problems with neonatal care occurred in only 19% of cases. In women without the care provided by a midwife, problems with the care of the newborn occurred in 37% of cases.

**Table 3** Occurrence of problems in the care of newborns according to the presence of a midwife

Midwife care	Problems with neonatal care		Total
	Yes	No	
Yes	19 (19%)	81 (81%)	48 (100%)
No	37 (37%)	63 (63%)	152 (100%)
<b>Total</b>	<b>56</b> (28%)	<b>144</b> (72%)	<b>200</b> (100%)

Chi-square test,  $p = 0.005$

A statistically significant correlation was also found between influencing factors of postpartum depression and midwifery care in the area of breastfeeding ( $p = 0.049$ ) (Table 4). Respondents who were at risk of postpartum depression and were visited by a midwife in the puerperium period had breastfeeding problems in 31% of cases, compared with women who did not have midwife care where breastfeeding problems occurred in 59% of cases.

**Table 4** Correlation between influencing factors of postpartum depression & midwifery care in the area of breastfeeding

Midwifery care	Breastfeeding problems		Total
	Yes	No	
Yes	8 (31%)	18 (69%)	26 (100%)
No	13 (59%)	9 (41%)	22 (100%)
<b>Total</b>	<b>21</b> (44%)	<b>27</b> (56%)	<b>48</b> (100%)

Chi-square test,  $p = 0.049$

We also compared the results of the EPDS scale in the experimental and control groups of women ( $n = 200$ ). We wanted to find out whether the care of a midwife has an effect on more frequent detection of postpartum depressive symptoms (Table 5). The risk of postpartum depres-

sion occurred in 26% of women in the experimental group and in 22% of women in the control group (Table 1). The distribution of the results of the EPDS scale did not differ statistically significantly ( $p = 0.775$ ) depending on the care or without the care of a midwife. In both groups, the category with a low risk of postpartum depression was the most represented (74% & 78%, respectively), the category with a high risk of postpartum depression was the least represented (8% & 6%, respectively) (Table 5).

**Table 5** Correlation between the risk of postpartum depression & care of a midwife

Midwifery care	EPDS results			Total
	Low risk of postpartum depression	Medium risk of postpartum depression	High risk of postpartum depression	
Yes	74 (74%)	18 (18%)	8 (8%)	100 (100%)
No	78 (78%)	16 (16%)	6 (6%)	100 (100%)
Total	152 (76%)	34 (17%)	14 (7%)	200 (100%)

Chi-square test,  $p = 0.775$

women with minimal interventions; support for women's natural abilities. Midwives who offer continuity of care often work in groups. The results of the research (9), which included 16,242 women, show that, compared with groups of women who were not cared for by a midwife, these women have lower rates of complications, and that the midwifery care has a positive effect on the mother-child relationship. This is confirmed by the fact that if a woman in the puerperium period does not profit from the care of a midwife, she may be more likely to have health complications, mother-neonatal interaction disorders or postpartum depression.

Women receive information about neonatal

## Discussion

The World Health Organization estimates that depression is the second leading cause of premature death and disability worldwide. Suffering from depression is still often underestimated. For every 1,000 live births, 100 to 150 women suffer from depression and one or two women suffer from postpartum psychosis (3). In recent years, there have been wide variations in postpartum depression ranging from 0 to 60%. In part, this is due to measurements to determine depression, as self-assessment scales are used; however, social and multicultural factors are likely to affect postpartum depression (7). Postpartum depression occurs in 10-15%, but some authors are of the opinion that the prevalence of postpartum depression of 10-15% is not representative (4).

In many parts of the world, midwives are the main providers of care for women during pregnancy, childbirth and puerperium period. Elsewhere, these are obstetricians, gynecologists or family doctors. The philosophy of midwifery should be: continuity; trustworthiness; care for

care in the hospital, from a pediatrician or from their midwife. In practice, we often encounter inconsistent information, which can subsequently lead to problems with the care of the newborn. These problems can cause a woman's stress, which is one of the possible factors that can affect the development of postpartum depression. Problems with neonatal care occurred in 56 respondents ( $n = 200$ ). In women at risk of postpartum depression, these problems occurred in 42% of cases, compared with women without any risk of postpartum depression (24%). According to the obtained results, a statistically significant correlation was found between the risk of postpartum depression and problems with neonatal care ( $p = 0.016$ ) (Table 2). Postpartum depression can impair a mother's ability to provide the necessary care for her baby. Children are very sensitive to the quality of care. Often, the mother-newborn interaction may be impaired.

In women with midwifery care, problems with neonatal care occurred in 19% of cases, and in women without midwifery care, in 37% of

cases. There was a statistically significant difference in the incidence of problems with neonatal care according to the presence of a midwife ( $p = 0.005$ ) (Table 3). This hypothesis confirmed that the care of a midwife has a preventive effect and is important. As already mentioned, the community care provided by a midwife in the Czech Republic is still considered as above-standard, for which in most cases women have to pay extra money. However, women often have no information about the services and the job description of midwives. Around the world, however, midwifery care is a standard service. In the United Kingdom, for example, women, in most cases, choose the care of a midwife (10). Similarly, in North America, almost 99% of women would choose midwifery care (11).

Every woman should know that breastfeeding is the ideal nutrition for their baby. There is a presumption (12) that breastfeeding could protect against postpartum depression. Breastfeeding has been shown to reduce cortisol in stressful situations. However, it has not been shown to reduce the risk of postpartum depression or that early termination of breastfeeding increases the risk of postpartum depression. In some cases, the pressure to breastfeed can be a significant stressor (12). However, our research suggests that there is a correlation between postpartum depression and breastfeeding problems ( $p = 0.049$ ). In respondents who were at risk of postpartum depression and were attended by a midwife in the puerperium period, breastfeeding problems occurred in 31% of cases, compared to women who did not have midwifery care where breastfeeding problems occurred in 59% of cases (Table 4).

The distribution of the results of the EPDS scale did not differ statistically significantly ( $p = 0.775$ ) depending on the care of a midwife. In both groups, the category with a low risk of postpartum depression was the most represented (74% and 78%, respectively); the category with a high risk of postpartum depression was the least represented (8% and 6%, respectively) (Table 5). The risk of postpartum depression occurred in 26% of women in the experimental group and in 22% of women in the control group (Table 1). Although the hypothesis was not confirmed and the incidence of postpartum depression is the same in both groups, we believe that early detection and care for women at risk of postpartum de-

pression can lead to alleviation or prevention of postpartum depression. This finding is also confirmed by research which shows that a midwife contributes to the prevention of postpartum depression through her care (13) and that her care also leads to improved mental health. Women who have received detailed information and individual care are less likely to have anxiety and depression than women without the necessary care and education (15). Support, understanding and counselling provided by midwives to women after childbirth leads to ensuring their mental well-being. Also, according to Skocir, Hundley (16), a midwife is the most suitable person to detect postpartum depression.

Postpartum depression is still underdiagnosed. Half of the midwives interviewed stated that they used a screening tool in their practice. Almost 60% of midwives also reported that the incidence of postpartum depression in their practice was lower than the incidence in the general population of 10-15% (17). Our research revealed the risk of postpartum depression in 24% of women, 26% in the experimental group of women and in 22% in the control group of women (Table 1). As the screening procedure for the detection of postpartum depression is irregular, the occurrence of postpartum depression in midwifery practice is also underestimated.

Although postpartum depression is a global issue, there are regional differences in prevalence and symptomatology. The prevalence of postpartum depression is influenced by countless local and environmental factors, cultural and ethnic elements, religion, healthcare or infrastructure. The EPDS is still the most widely used screening tool. Due to the high prevalence of postpartum depression, early diagnosis is important so as to enable the implementation of preventive measures in order to prevent the disease from progressing to a more serious form. Strategies that help develop the mother-child relationship are also important. Midwifery care for a woman in her puerperium period can be a potential benefit in postpartum depression screening (4).

It is clear from the survey that the care of a midwife leads to the prevention of health complications. Due to her care, a midwife does not identify symptoms of postpartum depression more often, but symptoms of postpartum depression are identified earlier, which she can then ad-

dress in time. Marks *et al.* (18) examined the effectiveness of community care in preventing postpartum depression. It turned out that the community care provided by a midwife does not have a decisive influence on psychiatric issues, but it was very successful in involving women in treatment. Therefore, community care is a significant benefit in caring for a mother with mental health problems. Dennis (6) confirms this statement and claims that intensive and professional postpartum care that a midwife can offer according to her competencies is the most promising intervention in the prevention of postpartum depression. In England, for example, there is a program used by midwives to help women after childbirth. The first part of the program is screening using the EPDS scale; the second part takes place at home. Although this is an established practice in England, for example in the USA, the second part of the English system is not used due to a different healthcare system (19). However, screening for postpartum depression by midwives in the United States is supported because it has been shown to be effective within primary care (20).

One of the world's largest organizations for postpartum depression is Postpartum Support International PSI, which has branches around the world. PSI was founded in 1987 in Santa Barbara, California, to bring together self-help groups in various countries. In addition, the association is also a member of a section which promotes interdisciplinary cooperation between various professional groups in the area of delivery of mentally ill women (21). There are not a large number of associations or societies in the Czech Republic that would be interested only in postpartum depression. Women who suffer from this disease can benefit from the help of organizations such as Smile Mom or Deprese.com - don't let the joy go. There is also a portal [www.help24.cz](http://www.help24.cz), which deals with the issue of human psychology and also provides free psychological counselling. The Psycho-Helpline also works.

The adoption of postpartum depression screening is necessary. The preparation and implementation of screening programs also requires the completion of many other steps, including staff training, the design of an appropriate screening tool, and the formulation and implementation of postpartum screening protocols (19).

## Conclusion

During the puerperium period, a woman requires special care. The woman's body returns to its original state before pregnancy and childbirth. The woman's psyche is also exposed to great strain. The results showed that the care provided by a midwife leads to the prevention of health complications in women in the puerperium period. The care of a midwife does not help identify postpartum depression more often, but symptoms are recognized earlier, and treatment is started. A midwife can also use her care to reduce the predisposition to postpartum depression. The women who were attended by a midwife showed fewer problems with breastfeeding or neonatal care, which are among the predictors of the risk of postpartum depression. Therefore, it is important to inform general public as well as the professional public about the services of a midwife and to get community care in the Czech Republic back to the forefront, thus eliminating the risk factors for postpartum depression.

We recommend: enabling midwives to work independently within their profession with the support of gynecologists and insurance companies; establishing family centers where midwives would provide postpartum community care and lactation counselling; providing comprehensive screening for postpartum depression using EPDS in community care or in gynecological clinics; providing training for midwives on postpartum depression and the screening methods, and supporting the establishment of self-help groups or counselling centers focused on postpartum depression.

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